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MOTHER-INFANT RELATIONSHIPS IN THE NICU:

A MULTIPLE CASE STUDY APPROACH

A DISSERTATION SUBMITTED TO

THE FACULTY OF THE GRADUATE SCHOOL

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BY

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shared their tremendous stories of strength, tragedy, fear, sadness, and hope. I am in awe

of your generosity and am humbled by your stories.

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ABSTRACT

Parent-child relationships consist of both external and internal components. The external component is the behavioral interaction between mother and child, while the internal components are expectations each member of the dyad has for the both the relationship and of the other partner. These expectations are called internal working models (IWMs) and are blueprints that have been developed from an individual's childhood experience of sensitive or insensitive parenting. A mother's IWMs influence how she perceives her child, her relationship with her child and herself as a mother, the sensitivity of her caregiving, and ultimately her child's IWM of him or her self.

Premature birth presents several challenges to the parent-child relationship and clearly impacts the external relationship features. Labor and delivery are often traumatic and are followed by abrupt separation of the dyad. The baby is taken into an environment that imposes physical separation, and is physiologically unable to participate in typical parent-child interactions. Until now there have been no studies that investigate the internal and external components of the relationship while in the NICU.

Cross-case findings from the study included three themes: (1) mothers experienced trauma; (2) the act of caregiving built the relationship; and (3) protocol-based caregiving at Midwest NICU interfered with the mother-infant relationship. While the research questions yielded the following findings: (1) a larger percentage of distorted internal working models was found in the present study than in previous studies that used the WMCI with preterm samples (Borghini, 2006; Korja, 2009; Meijsen, 2011; Tooten,

2014); (2) the quality of the behavioral interaction between mothers and their preterm infants during feeding was intrusive, regardless of the WMCI rating; (3) meeting the infant's attachment needs (e.g., successfully providing comfort during distress) in the NICU is what contributed to the participant's understanding of themselves as "good enough."

CHAPTER I

INTRODUCTION

Every year a half a million babies are born prematurely in the United States

(Hoyert, Mathews, Menacker, Strobino, & Guyer, 2006), a 30% increase since 1983

(Martin et al., 2005). With medical and technological advancements in recent decades,

infants born at 23-25 weeks now have a 40-60% chance of survival (Raju, 2006; Walsh &

Fanaroff, 2006). However, very small and sick infants have prolonged hospital stays in

the Neonatal Intensive Care Unit (NICU), which may place a significant strain on the

developing parent-child relationship.

Premature birth has long been recognized as a risk to the integrity of the parent-

child relationship. First, the premature infant presents with his or her own vulnerabilities

as he struggles to achieve physiological homeostasis and readiness to interact with the

environment. Second, the NICU environment imposes physical separation and limits the

mother's ability to make decisions about caregiving. Third, given that preterm delivery is

the result of a shortened pregnancy, theorists have proposed that the mothers' internal

working models (IWMs) of her child may also be premature (Stern, Bruschweiler-Stern,

& Freeland, 1998). Additionally, the NICU context presents a limited repertoire of

dyadic social interaction, which may further impair the mother's ability to elaborate upon

her IWM of her child and of herself as a mother.

Premature birth is a non-normative transition to parenthood, and has been referred

to as an "emotional crisis" (Caplan, Mason, & Kaplan, 1965) that typically evokes

feelings of grief and loss (Macey, Harmon, & Easterbrooks, 1987; Shaw, Deblois, Ikuta, Ginzburg, & Fleisher, 2006). Mothers, in particular, experience a sense of ambivalence, shame, guilt and failure (Shin, 2004). Furthermore, these feelings may continue well beyond discharge from the hospital (Kersting, Dorsch, & Wesselmann, 2004; Muller-Nix et al., 2004; Pierrehumbert, Nicole, Muller-Nix, Forcada-Guex, & Ansermet, 2003; Poehlmann, Schwichtenberg, Bolt, & Dilworth-Bart, 2009; Singer, Guo, Collin, Lilien, & Baley, 1999).

Not only do mothers (and fathers) experience a host of emotions surrounding their concern for their medically fragile infant, parents also grieve the loss of their role as parents (Callery, 2002). Parents may feel a sense of helplessness in this situation. Fathers in particular struggle with being unable to protect their infant from suffering, to alleviate the mother's pain (Lundqvist, Westas, & Hallstrom, 2007), to control what happens in the NICU (Arockiasamy, Holsti, & Albersheim, 2008) and to manage work related expectations (Pohlman, 2005).

Forming a bond or an attachment is a key developmental milestone for infants. However, thus far the literature has presented inconclusive evidence concerning the quality of preterm infants' attachment relationships and differences between term and preterm infants. In particular, the literature has yielded contradictory findings for the attachment quality of very and extremely low birth weight preterm infants.

For instance, the following studies noted a similar distribution of attachment infant quality (secure, insecure-avoidant and insecure-ambivalent) between preterm and full term groups (Brisch et al., 2005; Minde, Corter, & Goldberg, 1985; Rode, Change, Nian, Fisch, & Sroufe, 1981). Other studies have found that low risk (hospitalized for

less than a month) preterm infants did not differ from full term samples (Plunkett, Meisels, Stiefel, Pasick, & Roloff, 1986). It seems that preterm infants who present with greater health risks such as lower birth weight, born before 30 weeks gestation, and compromised respiratory ability, have a higher percentage of insecure attachments than preterm infants with fewer risk factors (Plunkett, Klein, & Meisels, 1988; Plunkett et al., 1986).

More recently, Brisch and colleagues (2005) attempted to explain attachment quality of very low birth weight (VLBW) infants via the status of the mothers' attachment quality to her own parents. They hypothesized that VLBW preterm infants may be at a higher risk of developing an insecure attachment as a result of maternal anxiety about the preterm infant's health status and development and the infant's own risk factors as a result of side effects from life-saving interventions received in the NICU. In this study both the mothers' and infants' attachment status were examined at 6 and 14 months respectively. They did not find a correlation between the mothers' and infants' attachment status. However, the VLBW infants with a neurological impairment were more likely to be insecurely attached.

Attachment in the preterm infant population has been primarily studied from the infant's perspective, or through the mother's attachment to her own parents. However, studies suggest that the attachment process of mothers to their infants may also be at risk (Borghini et al., 2006). In addition to the challenges presented by the physical separation of the mother and infant, mothers may suffer from trauma after the experience of premature birth (Kersting et al., 2004; Singer et al., 1999) that may impact their feelings and response toward their infant. Studies have indicated that mother-preterm infant

interactions differ from those of full term infants. Mothers of preterm infants have been noted to be intrusive, anxious, and controlling (Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix, 2006). Furthermore, preterm infants are more vulnerable to difficulties with regulation, attention, and neurodevelopment, thus placing the dyad at risk for further interaction difficulties.

<div align="center">**Problem Statement**</div>

Parent-child relationships consist of both external and internal components. The external component is the behavioral interaction between mother and child, while the internal components are expectations each member of the dyad has for both the relationship and the other partner, specifically in terms of responsiveness and care. The Internal Working Model (IWM) (Bowlby, 1969/1982), is a construct used to describe such expectations, and is a constantly evolving system of memories, beliefs, expectations, and emotions about one's self and others. The IWM influences what we expect of and from ourselves, others, and the world in general. IWM also directs how we perceive social relationships, the information that we retain, and how we respond. Through the experience of interaction with his mother, the young child develops a model of self by which he internalizes assumptions about how effective he is in using relationships for support, how valued he is, and how worthy he is of receiving care.

At present, a paucity of data exists regarding mothers' internal working models of their infants and of their relationship with their infant in the NICU. Three European studies (Borghini, et al., 2006; Korja et al., 2009; Korja et al., 2010) have evaluated maternal IWMs of NICU graduates at ages 6, 12, and 18 months. These studies address the relationship well after NICU discharge. A mother's perception of caregiving and of

the parent-child relationship appears to shift after discharge (Jackson, Ternestedt, & Schollin, 2003). Furthermore, data obtained from a European population may not be generalizable to the United States, given the more liberal social support provided to families in Europe that enables mothers to be more physically present during their infant's stay in the NICU.

Significance of the Study

The purpose of this study is to: (1) investigate internal and external features of the mother-preterm infant relationship within the atypical context of the NICU; (2) document how mothers develop an understanding of themselves as a mother and how they come to represent their infant in this context; (3) document experience of becoming a mother in a NICU in the United States.

CHAPTER II

REVIEW OF THE LITERATURE

The theoretical foundation is represented by attachment theory and the ecological systems model. Within attachment theory, I will focus on two related applications, the *components of a relationship* and the *caregiving system*. Lastly, I will discuss the ecological systems model and its application to the early parent-child relationship.

Conceptual Framework for Parent-Child Relationships

Attachment Theory (Including Caregiving System)

Attachment theory has been utilized as a conceptual framework for understanding the complexity of early parent-child relationships and justifying various interventions for the emerging relationship. In his book *Attachment and Loss,* Bowlby (1969/1982) conceptualized the parent-child relationship as part of an attachment and caregiving behavioral system that represents the foundations of the child's psychological development. The attachment system is a "care-seeking" system, so that the infant's behaviors are organized around remaining close to his caregiver (Cassidy, 2001). The reciprocal adult system is called the caregiving system, which organizes mothers' behaviors around the primary goal of maintaining the infant's proximity in order to ensure safety (Solomon & George, 1996). Bowlby (1969/1982) identified the primary caregiver's sensitive responses to her infant as one of the conditions that influence the development of a secure infant-caregiver attachment. According to this view, infants whose mothers respond promptly and sensitively to their cues learn that they can count

on their mothers when they need assistance and begin to form an understanding or
internal representation or a schema of themselves and others based on these experiences.
Although, the infant's attachment behaviors are initially biologically driven, as the infant
matures and begins to come into contact with others, his behavior will ultimately be
guided at the cognitive level by internal representations or internal working models of
attachment.

During the 1970s, Ainsworth made a breakthrough in terms of being able to
measure infant attachment style. She created an assessment situation called the Strange
Situation (SS). During a portion of the SS, the child is observed playing for
approximately 20 minutes, during that time their parent is first present but eventually
leaves for a few minutes and then a stranger enters the room. This paradigm is intended
to stimulate attachment-seeking behavior within the child; the child's response at the
reunion with the parent is believed to represent the security of the child's attachment to
his parent or other primary caregiver. His response is then categorized into secure,
insecure ambivalent, insecure avoidant, disorganized profiles. *Securely attached* children
explore the room freely while making visual or physical contact with his mother. When
an unfamiliar person enters the room, a secure child may feel comfortable interacting
with the stranger in his mother's presence, but not when he is alone. When their mother
returns, the securely attached child will seek comfort from her. It is believed that the
child is able to feel comforted by his mother because she has been sensitive to his needs
in the past and he has an expectation that she will comfort and soothe him. Securely
attached children are then able to return to play and exploration, feeling safety in

knowing that they can return to their secure base (their mother or other caregiver) to seek comfort if they become distressed again.

In contrast, children with an *anxious-resistant (insecure) attachment* are anxious when they are given the opportunity to play even when their mother is present. Her presence does not provide him with a sense of safety needed to explore toys available in this novel environment. When the mother departs, the child becomes very distressed and when she returns, he may cling to her or remain close to her but may be resentful, or he may behave angrily, hitting and pushing her when she returns. The anxiously attached child may also resist his mother's attempts to soothe him. This style of interaction often develops from inconsistent caregiving and insensitivity to their child's needs.

A child with an *avoidant insecure attachment* will display little emotional change when the caregiver leaves him alone in the room with the toys and will avoid or ignore his mother when she returns. He may treat the stranger in the same way he treats his mother. He may also run away from his mother when she approaches him or tries to console him. Children with this attachment style are believed to have received a disengaged and even rejecting style of parenting. The child does not have an expectation that his communicative attempts will be responded to.

Lastly, a child with a *disorganized attachment* does not demonstrate a coherent attachment strategy when the parent leaves and then returns. This is manifested in extremely diverse ways, including "acute and sometimes bizarre approach-avoidance conflict behavior; interruption or misdirection of ongoing behavioral patterns by seemingly contradictory, incompatible, stereotyped, or irrelevant behaviors; disorientation and confusion; and fearfulness toward the parent" (Solomon & George,

1999a, p. xiv). Several etiologies for disorganized attachment have been proposed: (1) the child's experience of a prolonged or repeated separations from his parent(s) (Solomon & George, 1999b); (2) parental rejection – as these behaviors both activate the child's attachment system and prevent the child from achieving a resolution (Solomon & George, 1999a, p. 12); (3) the child's experience of the parent as frightening and/or frightened (Main & Hesse, 1990); and (4) the loss of a parent during early childhood (Zeanah et al., 1999).

Main and Goldwyn (1984) extended the assessment of attachment behavior to include adult attachment styles of the participant's own parents via the Adult Attachment Interview (AAI). The AAI is an interview-based assessment that classifies a parent's state of mind with respect to his or her own parental attachment. Main, Kaplan, and Cassidy (1985) found a strong association between parent AAI scores and their child's behavior toward that parent during the Strange Situation. This was the first time that internal representations were considered as a likely mediator of differences in parental caregiving behavior (Hesse, 1999). The AAI contains 20 questions that inquire about individuals' experiences with his or her parents and other attachment figures, losses or trauma, and experiences with their own children. The interview is transcribed and then coded by a trained professional who has received approximately 18 months of reliability testing. The scoring process involves evaluating the individual's narrative for coherence, truthfulness, relevance, and richness. From analysis of AAI transcripts, patterns of internal representations can be found that are analogous to the behavior of children in the Strange Situation. These patterns are manifested not in the way the adults describe the events in their lives, but in the way such events were remembered and organized.

Main and colleagues originally described three patterns of adult attachment: autonomous, preoccupied, and dismissing patterns. *Autonomous* adults, like secure infants, are able to seek comfort and communicate distress in a clear manner. They have access to positive and negative components of their early attachment experiences and are thus able to make sense of these experiences in a balanced manner, appreciating the strengths and challenges of their upbringing. Whereas *preoccupied* adults are overwhelmed by affect associated with early attachment experiences. Like resistant infants, they are unable to regulate their emotions in order to communicate the need for comfort clearly. *Dismissing* adults, in contrast, describe early attachment experiences in a contradictory manner. They may idealize the early relationship experience and describe painful events in a detached fashion. Dismissing adults, like avoidant infants attempt to control their affect so that distress is not communicated and comfort is not sought.

Of note, insecure attachment as a child does not always predict an insecure attachment in adulthood (Main & Goldwyn, 1984). Adults who developed an "earned secure" attachment were able to critically reflect on their childhood by stepping back and considering his or her own cognitive processes as objects of thought and represent past experiences in a coherent and collaborative fashion. It appears that these adults tap into a means of "meta-cognitive monitoring" either through therapy or another means of self reflection and analysis in which they are able to construct or reconstruct a balanced representation by holding both the positive and negative components of one's past.

> Main suggests that coherence and the capacity to collaborate with the listener are the sequelae of the adults having formed a single, internally consistent working model of attachment; such a model allows for the integration of all attachment-relevant information and memories. All aspects of experience are allowed access to consciousness, without distortion or contradiction. (Slade, 1999, p. 580)

Further, the quality or security of an individual's representations of his or her own parents has been linked to the child's attachment to them (Benoit & Parker, 1994; Main, et al., 1985; Ward & Carlson, 1995) as well as the ongoing relationship to the child. As the parent is informed by his own representations or working models of relationships, the child is also gradually developing a working model of attachment based on how his parent cares for him. Over the first few years of life, working models become stabilized as expectations are developed of how relationships work and what one can expect of other people in terms of responsiveness and care. Through this experience, the young child also develops a model of self by which he internalizes assumptions about how effective he is in using relationships, how valued he is, and how worthy he is of receiving care.

When negative working models distort a parent's perception of his or her young child, it can create a cycle through which these subjective factors interact with the characteristics of the baby, creating distorted interactions that shape the child's behavior (Cramer & Stern, 1988). Young children are particularly susceptible to the deleterious impact of distorted interactions, as they do not yet have other life experiences or even the cognitive capacity to doubt the validity of their parents' impressions or to question the appropriateness of their parents' behavior. As a result young children may determine that their parents' negative representations of them are true and that their parents' abusive, dismissing, or tyrannical behavior toward them is deserved and in fact confirms that they are "bad." Furthermore, to cope with this distortion, they may develop defenses to protect themselves from this realization (Cassidy, 2001). These psychological defenses, which are adaptive in protecting the child from the frustration and pain caused by

attachment figures unavailability, become maladaptive when used in later relationship situations where secure strategies would be more effective. In order to sustain these strategies, a person has to build distorted working models and adopt ineffective affect regulation strategies, which are likely to interfere with subsequent development and hamper attempts to create rewarding close relationships (Mikulincer & Shaver, 2008).

Caregiving system. As discussed in the previous section, relationships contain both external (observable behavior) and internal components. The external component of the relationship has been called the *caregiving system*. According to Solomon and George (1996), the caregiving system is reciprocal to the attachment system within the infant. Within the attachment system, it is believed that the infant seeks his caregiver during times of stress or fear as a secure base. Within the caregiving system, the parent or caregiver seeks the infant in order to protect him. Caregiving is one of several parental (or other caregiver) motivational systems and may not always overlap with the infant's attachment system. For example, being a mother is not the only role a woman strives to fulfill, she may also be a wife, daughter, employee, a friend, and community member. Therefore, caregivers are seeking balance between their need to protect and nurture their child and their need to pursue other goals, just as infants seek to balance exploration with feeling secure in their caregiver's arms. As a result of the unique contribution of family contexts, culture and individual needs and desires, the manner in which a parent cares for their child will look different from parent to parent, child to child and family to family. Additionally, social pressures, social supports, the requirements of a particular child, and her own attachment experiences may influence her perception of danger or safety and thus alter caregiving behavior (Solomon & George, 1996, p. 186).

Therefore, the caregiving system is sensitive to the context the mother is living within; for instance, support may assist the mother with coping with the demands of caring for a young child. Support can be provided through conversations with friends or family or through relief of the physical demands of caregiving such as allowing the mother to rest while someone else does the laundry or cares for the baby. Without support and with the exposure to a stressful environment such as a demanding job, financial concerns, an unsafe community, family violence, or supporting a child with special needs, the mother's need to protect or support the infant may be impacted.

Maternal representations relate to internal working models of the infant as well as internal working models of caregiving. The mother's early attachment relationships influence not only her internal working model of her child, but also her internal working models of her own caregiving (George & Solomon, 1996). Therefore, the mother will have expectations for herself as a mother, what she feels is her role in caring for her child, how she responds to her child, what she perceives as dangerous, and what she expects from her child. Further, a number of researchers see the development of internal representations of the child as intrinsic to the development of internal representations of caregiving (or parenting) and the parent-child relationship (Bretherton, Biringen, Ridgeway, Maslin, & Sherman, 1989; Slade & Cohen, 1996; Zeanah, Benoit, Barton, & Regan, 1995).

Conceptualizing the parent-child relationship. Every relationship is complex and is derived from present as well as past experiences. When observing an interaction between parent and child, an outsider is only able to observe the behavioral interaction, the external component of the relationship. However, the behavioral interaction is also

driven by the internal component, which provides meaning to the given behavior. Just as both parent and child contribute behavior elements to an interaction, each member of the dyad also presents with internal representations and expectations of the other (Stern, 1995). Stern-Bruschweiler and Stern (1989) have presented a basic model for characterizing the infant-parent relationship, focusing on four components of the relationship. The components are: (1) the infant's overt interaction behaviors; (2) the mother's overt interactive behavior – thus presenting with two sides of a reciprocal interaction; (3) the mother's representation of that interaction; and (4) the infant's representation of the same interaction. Within this model, the relationship is seen as an open system so that these four components influence one another.

The external (behavioral) component of the relationship is evidenced by recurrent patterns of behavioral interaction between parent and child, such as the way the mother responds to her infant's cries, the way she feeds the baby, and the way she goes about interacting with her baby. In contrast, the internal component of the relationship is evidenced by recurrent patterns of subjective experience that may be influenced by the way the mother understands her infant, who the infant reminds her of, and how she feels about their relationship.

Internal representations pertain to the way experiences have been encoded in the mind and have been described within the context of various theoretical frameworks. Internal representations are conceptualized as "internal working models" in attachment theory, "mental representations" in psychoanalytic theory, "schematic structures" (Piaget & Inhelder, 1969) or "scripts" (Fivush, 1997) in cognitive and developmental psychology or the "representations of interaction that have been generalized (RIG)" in Stern's

integrative developmental clinical theory. *Internal working models (IWMs)* are mental representations specific to relationships and social emotional functioning, whereas schemas or scripts relate to cognitive functioning. This difference is relevant as a person's model or representation of relationships is often more prone to the influence of emotions such as love, hate, anguish, and shame and is also vulnerable to repression and the building of defenses (Karen, 1998). In contrast to Stern's (2000) *Representations of Interaction that have been Generalized (RIGs),* which are different in size and order from a working model, RIGs are the building blocks from which working models are constructed. The RIG is a representation of a specific type of interaction while the working model is a larger representation, an average of many episodes or specific interactions. For instance, a RIG may represent many specific experiences (like feeding, diapering, playing and so forth) that take place between mother and child, while the working model may represent the relationship between mother and child.

IWMs are used to structure a person's interpretation of social information such that beliefs and expectations of subsequent relationships are colored by one's previous experience of sensitive or insensitive care (Bretherton & Munholland, 1999). These IWMs influence a parent's behavior in caregiving relationships; parents work from their own internal working models of themselves as individuals as they construct meaning of social interactions with their own children. A mother's IWM of herself influences her perception of her own child and thus her interaction with her own child, thereby influencing her child's internal working model of himself (Ainsworth & Eichberg, 1991; Fonagy, Steele, & Steele, 1991; Main & Goldwyn, 1990).

Further, when early parent-child relationships suffer disturbances or significant challenges, treatment may target representations and/or behavior. These internal and external components of the parent child-relationship can be used as ports of entry in psychotherapy (Sameroff, 2004). When supporting parent-child relationships in this context, the patient is the mother-child dyad or sometimes the family triad. Relationship disturbances often manifest themselves in childhood regulatory issues, feeding problems, excessive crying, sadness, activity level, and/or difficulty sleeping. Parents may be suffering from depression, anxiety, other psychological challenges and/or maladaptive internal working models of relationships. Their past then colors the developing relationship as it continues to shape the infant's experience of himself and his experience of being in a relationship.

Parents' internal working models that were developed during their own childhood, developed before linguistic proficiency was in place. Therefore, these internalizations of early relationships are often processed as representations, rules, and models that can't be verbally accessed without support (Wallin, 2007b). Through therapy, an individual can make sense of what was originally learned in his or her early relationships and a new internal working model of relationships can be constructed. Additionally, parents' capacity for self-reflection and mindfulness of the present moment may be enhanced and used as tools to be more emotionally present in their relationship with their child.

Therapy may also target overt behavioral components of the early relationship. For instance, clinicians may support parents in learning behavior management strategies that are more effective, providing instruction in feeding or play. With this approach the

behavioral interaction (rather than the internal working model) is believed to be the immediate cause of difficulty within the relationship. However, based on current research there appear to be no differences between the results of either style of intervention (McDonough, 2004). It appears that each port of entry influences the other, as the behavioral intervention may influence the mothers' representations and the psychodynamic intervention may influence the parenting behavior.

Ecological Systems Model

When considering the early parent-child relationship it is also important to consider the larger context. Each dyad is embedded in and impacted by family relationships, culture, community, social support, community resources, economics, and policy. In his 1979 book *The Ecology of Human Development,* Bronfenbrenner emphasized the importance of the developmental context for human development. The parent and child within this system are parts of many interrelated ecological levels (nesting systems), which have an important impact on the child, the parent, the family and on the quality of life in society.

> Like a set of Russian dolls, the contexts of human development work in a nested fashion, each one expanding beyond but containing the smaller one. Each one also simultaneously influences and is influenced by the others. Thus the context of the family fits into that of the neighborhood; the context of the neighborhood into the larger contexts of city, work and government; and all contexts into the largest context of culture. Whatever factors affect any larger context filter down to affect the innermost unit, the family. (Bronfenbrenner, 2005, p. 261)

These nesting systems are also described as the microsytem, mesosytem, exosystem, and macrosystem. At the center of the nesting system is the developing human being. The ecology of human development involves the "scientific study of the progressive, mutual accommodation between an active, growing human being, and the

changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings and by the larger contexts in which the settings are embedded" (Bronfenbrenner, 1979, p. 21). In this definition, Bronfenbrenner notes that the child is not regarded as a blank slate, he regards development as a dynamic, reciprocal interaction between biology and the environment. He further clarifies through his description of the various nesting systems that the environment is not limited to a single, immediate setting, but is extended to incorporate interconnections between such settings, as well as to external influences originating from the larger surroundings. The *microsystem* pertains to the individual's immediate environment (setting) and the activities, roles and interpersonal relationships he or she engages in. Settings are places where people can readily engage in interaction, they refer to any home, day care, playground etc. The environment at the microsystem level is phenomenological. A *mesosystem* pertains to a set of microsystems within an individual's developmental niche during a given point in time. The *exosystem* pertains to contexts that involve the child indirectly, such as his parents' work, school attended by older sibling, the parents' network of friends, the activities of the local school board and so on. The *macrosystem* refers to the "superordinate level of the ecology of human development"; it is the level involving culture, macroinstitutions (such as the federal government) and public policy. The macrosystem influences the nature of interaction within all other levels of the ecology of human development (Lerner, Dowling, & Chaudhuri, 2005, p. xiv).

Bronfenbrenner's (1979) model allows us to better understand how and why each individual's developmental context is unique, and as a result, each individual's

experience in this world is unique. As a result, each parent and each family will raise their child differently given the dynamic influence of the nesting systems. Further, the macrosystem has the power to influence all nesting levels. Culture is one element of this superordinate system that has the unique role of not only influencing all nesting levels but of influencing behavior as well as how information is interpreted. Culture is, in fact, what gives meaning to human behavior.

Anthropologist Edward T. Hall (1977) stated, "there is not one aspect of human life that is not touched and altered by culture" (p. 16). Cultural norms influence parents' assumptions about child rearing as well as expectations for their child's behavior. As a result, a child's ability to express himself emotionally is strongly influenced by the assumptions about the nature of emotional life held by adults in his social sphere (Miller & Sperry, 1987). "Through the childrearing process, parents transmit the rights and wrongs of the society, and other knowledge they consider to be important for their children. This process begins at birth and is transmitted through a family system that is imbedded in a larger societal and cultural context" (Garcia-Coll & Meyer, 1993, p. 56). This process is then further influenced by the complex interplay between a parent's life experiences and his or her beliefs or values that influence interpretation of behavior in context and emotional socialization. Further, internal working models of caregiving are also influenced by what Garcia-Coll and colleagues (1996) have referred to as an integrative model for developmental competencies in minority children. The model focuses on three aspects of context: (1) social position (race, social class, ethnicity, gender); (2) racism, prejudice, discrimination and oppression; and (3) segregation. For children who are minorities, these pathways can work in synergy to create different and

even hostile experiences that ultimately influence how children develop. Further, Ogbu (1981) suggests that parents are aware of these contexts and that they raise their children with the skills necessary to navigate through their unique context. Therefore, it is clear that different contexts require different skills and that there is no universally optimal caretaking strategy.

Summary

In summary, relationships between young children and their caregivers are complex, dynamic, and powerful. They have the capacity to support or interfere with the child's developing self-esteem, his ability to seek and maintain mutually satisfying close relationships, and to the provision of a supportive emotional environment for his or her own offspring. I have attempted to explain the multifaceted nature of these early relationships through the application of both attachment theory and the ecological model of human development.

Attachment theory, along with the *caregiving system,* explains the relationship in terms of internal and external components. Behavioral interaction between the mother and the small child is conceptualized in attachment theory as the child's proximity seeking and exploration. The child seeks his caregiver in order to feel safe, supported, and/or assured. The child also desires to learn about his environment and those around him and will explore by moving away from his caregiver. Although the caregiving system is motivated to protect the child, caregiving goals are not always in line with the child's attachment goals. A child may see an opportunity to explore, while the parent may perceive danger. Further, parents must balance this goal with other priorities such as

paying bills, cleaning the home, cooking meals, working outside the home, sustaining other social relationships, religious obligations, other responsibilities, and so forth.

The behavior of both the child and the adult is governed by their own internal representations of themselves, of one another, and of their relationship. In fact, these mental representations or internal working models filter how one receives information, which information is perceived as salient, how one sees himself, and how one behaves or acts on this information. For a young child, these internal working models are formed in his early relationships and remain a powerful influence on his social and emotional development.

Finally, parenting practices are shaped by cultural norms. Bronfenbrenner's ecological model of human development further illustrates how each individual's developmental context is unique through the reciprocal interaction between individual biological predispositions and the environment. The environment is characterized as the parent-child relationship nested within the family system, which is nested in the neighborhood the family lives in. The neighborhood is further impact by the city in which the neighborhood is located, the country that the city is located in, and the government's rules and regulations, as well as by the culture that that family identifies with. Following this theoretical examination of parent child relationships, we now move to the examination of internal representations, specifically the factors that influence the development of maternal internal representations.

Maternal Internal Representations

Development of Maternal Internal Representations

Several factors have been found to influence maternal internal representations: (a) attachment status to the mother's parents and the quality of her relationship with her significant other; (b) social support; (c) mental health; (d) reflective function; and (e) infant biological vulnerabilities. Each of these factors will be discussed below.

Quality of relationships. Numerous studies have supported the powerful link between the quality of parents' early relationships and their internal representation of those experiences to the quality of their own child's attachment to them (Benoit & Parker, 1994; Fonagy, Steele & Steele, 1991; Levine, Tuber, Slade, & Ward, 1991; Zeanah, et al., 1995; Zeanah, Mammen, & Lieberman, 1993). In her seminal paper, *Ghosts in the Nursery,* Selma Fraiberg (1975) presented a series of case studies to support the influence of a mother's past relationships with her own parents on her ability to perceive and respond to her child. Although insecure relationships often correlated with distorted maternal representations and insensitive care, Fraiberg concluded that the presence of insecure relationships and even events of abuse, tyranny and desertion, did not necessarily predict that parents would pass on these experiences to their own children. Rather, it was the memory of the affective experience – the emotions one felt during these experiences – that was associated with a break in the intergenerational transmission of attachment disorders as parents were able to identify with those emotions that "saved them from the blind repetition of that morbid past" (p. 23). It was hypothesized that access to the childhood pain is a powerful deterrent against repeating the past, while

repression of the painful affect "provides the psychological requirements for identification with the betrayers and the aggressors" (p. 23).

In addition to past relationships with one's parents, present relationships also influence a mother's representation of her child. For instance, Sokolowski, Hans, and Bernstein (2010) studied the associations between mothers' representations of their infants and parenting behavior with mothers' psychological distress and exposure to verbal and violent relationships. Relationship conflict (with either their own mother or their child's father) was related to the representation the mothers formed of their own child. Mothers who experienced verbal conflict with their own mothers tended to have a disengaged representation (similar to a dismissive rating on the AAI) of their own infant. The mothers experienced the verbal conflict from their mothers as rejection and, in turn, became rejecting of their own infants. In fact, it has been proposed that disengaged mothers may not be willing to acknowledge feelings of need in their own children, so they reject their children during these times as they remind them of the pain of rejection by their own mothers (Fonagy et al., 1991). When mothers reported more verbal and violent conflict with their infants' fathers, the odds of having distorted representation (similar to a preoccupied rating on the AAI) of their children increased. The researchers proposed two explanations: (1) that worries about fathers' verbal and violent abuse may directly interfere with women's relationships with their own children; (2) a generalized stance toward relationships is a cause of both the conflict and the representations. For instance, perhaps they had a similar relationship with their own parents and thus unconsciously sought out a similar partner.

When mothers are supported by their husbands or significant others or other

family members, they are more likely to have securely attached children (Belsky,

Rosenburger, & Crnic, 1995). Although empirical research has not yet explored the

relationship between maternal representations and the family system, information does

exist regarding the relationship between attachment and family systems theories. For

instance, Hill, Fonagy, Safier, and Sargent (2003) conceptualized the attachment process

within the family. The key components of the attachment process focus on the

individual, but are also applicable in a family system. The components include: affect

regulation, interpersonal understanding, information processing, and the provision of

comfort within intimate relationships. When considering mental representation, there is

considerable overlap between family systems theory and attachment theory.

> Family systems theories have discussed the multigenerational transmission
> process and nuclear family emotional process, family belief systems, with the
> notion that historical experience and the stories that develop from that experience
> form the basis of working narratives that are repeatedly enacted by the family.
> Attachment theorists similarly hold that historical experience forms the basis for
> internal working models that also set the stage for how individuals, and we would
> assert, families, approach certain developmental tasks. (Hill et al., 2003, p. 211)

Family systems contain their own family scripts (Byng-Hall, 1999) or shared

working models (Marvin & Steward, 1990) of expectations and beliefs about various

contexts of family life such as meal times, role expectations, and ways of being together

as a family. It is particularly important for family members to understand one another's

working models in order to facilitate a shared working model, which will allow each

family member to anticipate one another's plans and actions (Marvin & Steward, 1990).

In the case of a new mother, a shared working model can perhaps assist other family

members in understanding what the new mother's expectations for assistance may be, or

what the expectations for support may look like within the family system. Additionally, a shared working model of the family may assist the mother in knowing when to mobilize resources or when to expect limited support.

Social support. Social support is a broad term that generally involves close relationships with spouse, extended family, good friends, and other social networks so that it allows one to exchange material goods, information and problem solving strategies (Brandt & Weinert, 1981). Social support may also allow the individual to feel cared for, loved and understood (Cobb, 1976). New mothers are particularly vulnerable to the needs for social support. Given the increased physiological and emotional demands of pregnancy, women grow more dependent on others during this time; they not only rely on their own mothers and husbands or significant others for support, but they also need the support of other women – particularly other mothers. In Stern's description of the *supportive matrix theme*, other women are essential in developing a "holding environment" for the mother to care for her infant and assume her new responsibilities. This psychological holding environment is also important in how the new mother develops her representation of her new child.

Further, evidence suggests a strong association between levels of social support and a range of parenting outcomes from positive to negative qualities in parenting, including sensitive parenting, improved maternal psychological wellbeing, improved child outcomes, parental self-efficacy and feelings of isolation (Andersen & Telleen, 1992). Perhaps because support is an important element in reducing depressive or anxious symptoms for post-partum women (Goodman & Gotlib, 1999), an increase in these symptoms, particularly clinically significant symptoms, can then impact the way a

new mother represents her newborn child and her own experience as a mother (Belsky et al., 1995). Therefore, social support can *moderate* the impact of an event - such as becoming a parent - as the impact of an event depends on how that event is perceived and experienced by the individual (Bronfenbrenner, 1979; Crnic, Greenberg, Ragozin, Robinson, & Basham, 1983; Crockenberg, 1986).

Although research has not directly linked social support to maternal representations, studies provide reason to consider the relationship, particularly for infants who are considered "high risk" (i.e., colic, fussiness, prematurity). Crockenberg (1981) conducted a study examining the contribution of infant characteristics and maternal behavior on the development of secure infant mother attachment; the researchers also assessed the influence of mothers' social support on her responsiveness to her baby and the child's subsequent attachment. Social support was conceptualized as reflecting the "functional adequacy of support to the needs of the specific mothers" (p. 859). Therefore, the number of stressors was subtracted from the support ratings. Findings indicated that mothers of both high irritable and low irritable infants had primarily securely attached infants as long as they received high levels of social support. When mothers received low levels of social support, a majority of the highly irritable infants were anxiously attached, while the majority of infants with low irritability were securely attached. Therefore, it appears that social support is particularly important for the mother-child relationship when infants are fussy and mothers may be unable to help in co-regulation.

Mental health. A woman's mental health may also influence the quality of internal representations of her child as well as the quality of her relationship with her

child.   In general, meta-analytic studies have found a modest association between

maternal depression and insecure attachment (Atkinson et al., 2000; van Ijzendoorn,

Schuengel, & Bakersman-Kranenburg, 1999). Young children who are cared for by a

caregiver who has depression may struggle to develop a secure relationship and thus may

develop a negative representation of themselves as well as others (Goodman & Gotlib,

2002; Lyons-Ruth, Connell, Grunebaum, & Botein, 1990). Further, negative internal

working models are hypothesized to increase an individual's vulnerability to depression.

For instance, studies have found an association between negative internal working

models and elevated levels of depressive symptoms in children (Abela et al., 2005;

Abela, Zinck, Kryger, Zilber, & Hankin, 2009; Grahm & Easterbrooks, 2000) and adults

(Carnelley, Pietromonaco, & Jaffe, 1994). In addition to impacting relationships and

perception of themselves, maternal depression may be responsible for initiating a

downward cycle of challenges to the overall development and well being of the young

child.

> Development is seen as consisting of a hierarchically organized series of stage
> salient tasks that become increasingly differentiated over time. At each point of
> reorganization, prior developmental structures are incorporated into subsequent
> ones. Thus, the effects of being reared by depressed parents are likely to be
> carried forward within the existing organization of systems. As such, previous
> vulnerabilities or strengths are expected to remain present and to influence future
> adaptation. (Toth, Rogosch, Sturge-Apple, & Cicchetti, 2009, p. 192)

The way in which depression impacts the parent child relationship is an ongoing area of

study. One of the pathways studied has been the mother's ability to parent her child in a

responsive and sensitive manner. Researchers have begun to identify that depressed

mothers may behave in an unresponsive, intrusive and/or unpredictable manner

(Goodman & Brand, 2009). All three of these characteristics are associated with

challenges to infant mental health and can actually lead to brain-based changes as a result of increased cortisol levels associated with stress (Dawson et al., 2003; Field, 2002). For example, unresponsive caregiving limits the infant's access to co-regulation during moments of stress.

According to the *Mutual Regulation Model* (Tronick, 2007), such failure can lead to the infant's difficulty in developing arousal modulation, which will continue to impact their level of irritability and capacity to cope in moments when parents are not responsive to their needs. Infants who experience unpredictable parenting (alternating withdrawn and intrusive modes of interacting) may experience this pattern as particularly stressful and may develop reduced left frontal electrical brain activity (Goodman & Brand, 2009). Therefore, maternal depression may set the stage for challenging behaviors from the infant and perhaps decreased pleasure derived from the parent-infant relationship.

According to psychoanalytic theory and attachment theory, behavior within relationships is driven by internal representations; a further direction for research could be to study how depression impacts mothers' internal working models of their child, their relationship with their child and their perception of themselves as caregivers. Given that depression impacts maternal behavior as well as the young child's internal working models, it seems likely that maternal depression impacts mothers on a representational level as well. This line of research seems particularly salient for mothers who may have other factors that present as a risk to the parent child relationship such as limited social support, financial constraints, maternal or infant health problems, or infant irritability.

Reflective functioning. Reflective functioning refers to the "essential human capacity to understand behavior in light of underlying mental states and intentions"

(Slade, 2005, p. 269). The construct has been drawn from Fonagy's work on mentalizing. *Mentalizing* refers to the process by which we realize that having a intellect arbitrates our experience of the world, it relates not only to self-knowledge but to knowledge of the minds of others (Wallin, 2007a).

> Reflective function allows us to see ourselves and others as beings with psychological depth. It enables us to respond to our experience on the basis not only of observed behavior, but also of the underlying mental states – desires, feelings, beliefs – that make behavior understandable and give it meaning. As such, reflective function is intimately related to our capacities for insight and empathy. (Wallin, 2007a, p. 44)

Fonagy and colleagues constructed the Reflective Functioning Scale, in which a strong mentalizing capacity was operationalized as: (1) an awareness of the nature of mental states; (2) explicit effort to identify mental states underlying behavior; (3) recognition of the developmental aspects of mental states – that parents' behavior is shaped by their own parents' behavior and shapes the behavior of their children and that childhood perspectives often need to be revised in light of adult understanding; and (4) awareness of mental states in relation to the interviewer (Fonagy, Target, Steele, & Steele, 1998).

As mentioned previously in the discussion of Fraiberg's work, parents who are able to interrupt the process of intergenerational transmission of attachment disorders have access to memories of painful early affect, which makes them attuned to their child's fear and sadness and motivates them to change their child's life for the better. Such a change requires reflective functioning, the parent's capacity to represent and understand the breadth of her child's internal experience. "A reflective parent grasps the complex interplay between her own state of mind and that of her child, between her

internal experience and her behavior and between her child's internal experience and behavior. A reflective parent uses such understanding to guide her behavior; thus, reflective functioning in a very real sense is central to her capacity to respond sensitively" (Slade, 2005, p. 279). Highly reflective parents understand themselves and how their emotions work and understand their child's behavior and feelings. Further, a greater capacity for mentalization implies that the mother would be able to view her child as having a separate and distinct mind from her own. This capacity is a prerequisite for the formation of coherent and balanced representations of the child (Schechter et al., 2005). Further, it seems that higher levels of reflective functioning are associated with balanced maternal representations of the child and that low levels of reflective functioning are associated with disengaged representations as measured via the Working Model of the Child Interview (Schechter et al., 2005).

Infant biological vulnerabilities. There are a number of infant biological vulnerabilities that have the potential to impact the mother's internal representation. Two important vulnerabilities are an infant's temperament and the infant's regulatory capacity, as they directly influence how the infant responds to various inputs, including interaction with his mother or caregiver. It appears that either of these infant-specific traits are only vulnerabilities or risk factors when they are combined with other parent risk factors.

Temperament. Temperament is a stable tendency to reacting to situations and/or expressing behavior; it is shaped by genetics, constitution, and environment (Lieberman, 1995). Thomas and Chess (1977) identified three characteristic patterns of temperament: easy, difficult, and behaviorally inhibited. Children with an *easy* temperament are flexible; they are usually in a good mood, demonstrate stable biological rhythms (i.e.,

sleeping, eating, toileting), adapt to new situations and are mildly or moderately intense in their emotional reactions. Because of these traits, "easy" children integrate into the rhythms of the household. While children with *difficult* temperaments often demonstrate irregular biological rhythms, they have a hard time coping with changes in routine or new situations, become moody easily and have intense emotional reactions. Lastly, children who are *behaviorally inhibited* acclimate to new situations slowly – they may withdraw at first, spend time observing the new situation, but will eventually adapt. They tend to express their emotions in a subtle manner.

According to the *mutual regulation model* (Brazelton, 1974, 1982; Tronick, 1980, 1982), the infant contributes to the early parent child relationship. Further, an infant's temperament or constitutional variability can have a tremendous influence on parent's perception of the child and subsequent caregiving behavior. While difficult temperament in infancy (under four months of age) has not been found to be a stable characteristic (Hubert, Wachs, Peters-Martin, & Gandour, 1982), these tendencies may be exacerbated or minimized based on how a child's parents interact with both the child and the structure of his environment.

Temperament implies a stable set of traits that filters how a person responds to and perceives various situations. In contrast, self-regulation is influenced by how sensation is perceived and responded to (Greenspan & Wieder, 1993). Both channels of sensory processing (perception) and motor planning (action) influence how one is able to negotiate with and adjust to their caregivers and environment. When a child has a regulatory disorder, they may have difficulties regulating physiological, sensory, attentional, motor or affective processes. Additionally, they may have difficulty

organizing a calm, alert, or affectively positive state. Newborns are capable of engaging in self-soothing activities such as sucking on their fingers, focusing on an object, snuggling into a caregiver or a soft border in their crib. However, self-regulation in terms of managing the onset of crying, regulating sleep cycles and motor processes is an evolving capability for the young child. For instance, after the first biobehavioral shift, which takes place around three months of age, an infant is able to differentiate cries to express different needs and emotional states (Emde, 1989). As a result, the frequency of fussy behavior diminishes, as the infant is able to use crying to communicate more specific needs. However, for some infants, prolonged crying continues beyond this first biobehavioral shift. Furthermore, when the fussing or crying continues for more that three hours a day, for three days a week and for at least three weeks, the infant may be considered to have *colic* (Wessel, Cogg, Jackson, Harris, & Detwiler, 1954).

Infant's regulatory capacity. Colic is characterized by excessive and inconsolable crying, hypertonicity and wakefulness that cluster in the evening hours (Lucassen, Assendelft, van Eijk, & Gubbels, 2001). Prolonged infant crying creates an adaptive hurdle for the infant and his parents. Studies have not directly assessed the impact or association between infant temperament and self-regulation to mother's internal working models of their child and of themselves as caregivers, however, research has shown that it is very stressful for the family and may negatively impact how the mother views her competence as a mother. In one study (Stifter & Bono, 1998), mothers of infants who had colic rated themselves as less competent than the control group. These findings are in line with other studies that have linked colic to increased family stress and diminished parent confidence (DeGangi, Porges, Sickel, & Greenspan, 1993;

Lester, Boukydis, Garcia Coll, & Hole, 1990; Papousek & Von Hofacker, 1998). Given

that infants with colic cry for an average of three hours for at least three days a week, it is

not surprising that mothers may begin to begin to feel frustrated and helpless (Donovan &

Leavitt, 1985). Furthermore, prolonged feelings of frustration, helplessness and a sense

of incompetence may lead to a sense of malaise.

It is important to note that despite the challenges that a fussy infant presents, some

parents learn to reduce irritability or tolerate it and support the infant through it. They

may explore different strategies such as swaddling, rocking, white noise or monitoring

the degree of sensory input. Parents may alter the way they communicate with their child

or the way they expose them to new stimuli knowing what their preferences may be. For

instance, if an infant is sensitive to sound, his parents may speak to him quietly and be

mindful of the sorts of situations they expose him to. If a child seems to be sensitive to

multiple sensory inputs such as auditory, visual and tactile input, a parent may explore

various combinations of reducing stimulation in order for the infant to feel comfortable

interacting with his environment. In these cases, the parent has the necessary resources to

support their infant and is able to alter their environment to accommodate the infant. In

other cases, parents may become frustrated, anxious, or even angry. Their responses may

not be adaptive to the infant, they may shout at the baby, withdraw emotionally, and

leave him to cry it out, and/or inflict physical punishment. These are examples of what

Thomas and Chess (1977) have referred to as the absence of "goodness of fit."

The goodness of fit between the child's temperament or self regulatory capacity

and the mother's capacity to provide sensitive care will not only impact the child's ability

to self-regulate at the time, but will impact the attachment process between mother and

child. Although there aren't any studies to date, it seems likely that goodness of fit would

also impact the mother's representations of the child as well as of herself as a caregiver.

Summary of the development of maternal internal representations. I have

reviewed five factors and their influence on the mother's internal working model of her

child. These factors include: (1) quality of the mother's relationships; (2) social support;

(3) mental health; (4) reflective function; and (5) infant biological vulnerabilities.

Undoubtedly, relationships impact one another, but early relationships in

particular have a large impact on future relationships. Researchers have studied early

relationships from several angles. Links have been noted between (1) maternal

representations of their child and their representation of their relationship with their own

parents, (2) the child's security of attachment (also based on internal representation) to

his parents and his parents internal representation of his own parents, and (3) the child's

security of attachment to his parents and his parents internal representation of the child.

Further, maternal representations are influenced by both past relationships (Fraiberg,

Adelson, & Shapiro, 1975) and present relationships (Sokolowski, Hans, & Bernstein,

2010). For example, the security of the mother's attachment to her parents may impact

the clarity of her internal representation of herself as a person, caregiver, and significant

other. Further, mothers who experienced verbal conflict with their own mothers tended

to have a disengaged representation of their own infant. In contrast, mothers who have

verbal or violent conflict with their infant's fathers, have a higher likelihood of having a

distorted internal representation of their own infant.

In this review social support is meant to encompass extended family, friends and

other social networks that allow the mother to feel cared for through exchange of material

goods, information and problem solving. Although social support is clearly related to the quality of relationships with the mother's parents and significant other, I have defined them separately, and considered social support as a broader framework that encompasses relationship quality with many different types of individuals (family, friends, acquaintances, social networks). Further, social support can relate to various means of being cared for that is not accounted for through studying the quality of relationships via attachment style. For instance, discussions with other parents of premature infants on a social network website, may provide tremendous support, but have little to do with the quality of relationships with those individuals on the network. In fact, social support can moderate the impact of a traumatic or intense event (such as becoming a parent) as the impact of the event is dependent on how the event is perceived by the individual and certain types of social support may provide an opportunity for reflection. Although research has not directly linked social support to maternal representations, studies have found that for mothers of highly irritable infants social support impacted the security of the infant's attachment to his mother.

Maternal psychological well-being may also impact the security of attachment between mother and child; it may also impact how readily the mother seeks out social support. Several studies have examined the relationship between maternal depression and the quality of her relationship with her child. Results have noted that mothers with depression may be more likely to be unresponsive, intrusive, and unpredictable. All three of these characteristics are associated with challenges to infant mental health and can impact brain development through increased cortisol levels associated with stress. Further, young children who are cared for by a depressed caregiver are more likely to

have difficulty controlling their arousal as they have had limited experience with co-regulation, given the parent's limited availability. Therefore, maternal depression may set the stage for insensitive parenting, and challenging behaviors from the infant and perhaps reduce the mutual pleasure each member of the dyad experiences.

Reflective function relates to awareness of one's mental state, efforts to identify mental states underlying behavior, and recognition of the developmental nature of mental states. A reflective parent is able to use such understanding to guide behavior, thus impacting caregiving sensitivity. Higher levels of reflective functioning are associated with balanced maternal representation of the child and low levels are associated with disengaged representations (Schechter et al., 2005). Unfortunately, mothers who have mental health challenges may be less reflective as well.

Infant biological vulnerabilities impact how much the infant demands of the relationship. Two important vulnerabilities are an infant's temperament and regulatory capacity as they directly impact how an infant responds to social interaction, daily routines, separations, and challenges posed by exploring the environment. Further, the goodness of fit between parent and child can greatly influence how parents interact with the child and structure his environment. For instance, some parents who have fussy infants may respond sensitively to the infant's increased needs for support and may therefore impact the child's ability to self-regulate.

Five factors have been reviewed in this section as impacting maternal internal representations either directly or indirectly. Further, it seems that many of these variables may work in tandem to exacerbate an already challenging situation or they may work to further facilitate healthy relationships. These variables further emphasize the influence of

context on early relationships, particularly socio-economic resources, psychological health, age of the mother, the neighborhood the mother is living in and so forth.

Development of Maternal Representations in Pregnancy

Pregnancy has been considered a preparation for motherhood, a marker in a woman's life, as well as an identity process. It is a transitional time that results in a reorganization of relationships both personal and professional, a time of reorganizing priorities, shifting life focus, and a redefined identity. Rubin (1975) is often credited for her pioneering work on woman's attainment of the maternal role. She postulated that women go through progressive stages that begin during pregnancy and end in maternal role identity. They include safe passage, acceptance of the child by significant others, binding in, and giving of oneself.

Safe passage begins in the first trimester of pregnancy and relates to a woman seeking and ensuring safe passage through pregnancy and childbirth. At this point, concern for safety is related to herself, not the baby. As the second trimester emerges, the woman's awareness of her growing child increases, and as a result she attaches much value and importance to him. In the third trimester, the woman is now concerned with herself and the baby, her body has grown considerably thus impacting her mobility and ability to access her environment in the same way. Therefore, daily tasks that were once simple become tremendous obstacles, such as passing through revolving doors, putting on shoes, getting dressed, climbing stairs, negotiating crowds, etc. As a result, her sense of protectiveness of both herself and the baby increases. *Acceptance of the child by significant others* is a critical task and is just as important as seeking safe passage. "The fact that women who are pregnant are most concerned with this aspect in the first short

trimester and again early in the third trimester seems to indicate that security in

acceptance is a condition necessary to produce and sustain the energy for all other tasks"

(Rubin, 1975, p. 4). Further, it falls upon the mother to organize the necessary social and

physical accommodation within the family and household for the new baby. While the

physical accommodation can be straight-forward, the psychosocial accommodation can

be far more complicated.

> Each relationship the pregnant woman has with each member of her family household is unique. Each relationship has its own bonds of intimacy and exclusiveness, its own history and culture, its own sets of mutual commitments and expectations. It is these bonds that must be loosened, but not broken, and realigned so that the bonds endure and continue despite changes in the degree of exclusiveness and expectations. To a lesser degree, relationship bonds must be loosened and realigned outside of the family…Each relationship bond is an achieved bond that is not easily relinquished in any degree by either member of the relationship. There is a normal, healthy resistance to the loosening and realignment of meaningful ties. (Rubin, 1975, p. 4)

As the pregnancy progresses, acceptance and accommodation become critical issues that

are inextricably paired; if acceptance is low, rejection is high. Further, the woman's need

for acceptance is high during this time and her sensitivity to rejection is high as well.

Therefore, if her family and significant others express ambivalence or accept the child

conditionally (based on sex, health, living up to a specific standard or relationship), this

may prove to have significant consequences for how the mother reformulates her own

identity and incorporates the new relationship into existing relationships. This work of

reintegration leads to the process of *binding in*. The bond between mother and her child

continues to emerge throughout the pregnancy. At birth there is already a sense of

knowing the child, a sense of shared history, a special intimacy as mother and child have

shared one body.

Binding-in to the idea of the child, her child during pregnancy is an incorporation into the woman's entire self-system: into her body image, her self-image, and her ideal image. The entire mental apparatus, the unconscious, the preconscious, and the conscious, not just one or another part of the mind, is used in this incorporation. Motivation, wishes, and fears play a large determining part in the rate and extent of binding-in. Both the child within and the environment around her provide inputs, but all inputs are mediated through the body image, the self-image, and the ideal image for acceptance or rejection. (Rubin, 1975, p. 5)

The mother's ability to bind-in increases significantly during the second trimester as she begins to perceive her baby's movements; thus increasing the pace of feeling pregnant as well as the determination to undertake the tasks of pregnancy. Throughout the second trimester, the mother's awareness and understanding of the child increases, thus furthering her love of both the child and her sense of self. The last trimester brings on challenges as she wants the child but dislikes the pregnancy. *Giving of oneself* is brought on by the pregnancy and ultimately the labor and delivery. Rubin (1975) describes the final maternal psychosocial stage as:

one of most intricate tasks of pregnancy, of mothering, and of adulthood itself. The pregnant woman engages in this task in amore concentrated period of time and with more intensive and extensive involvement. A demanding child is more consuming, more threatening, and more uncontrollable in utero that in the outer world. On the other hand, the child in utero can be experienced as a gift given to her and simultaneously a gift she gives to others. All three experiences are part of pregnancy and of mothering. (p. 6)

Just as Rubin (1975) described the process of maternal role attainment in psychosocial stages, other theorists have described the psychological organization that takes place during pregnancy. For instance, Bowlby (1988) believed that while the infant's biological predisposition is to become attached to others, it occurs within the context of an equally strong biological inclination in the parent – to care for the child. The caregiving system is believed to be activated over the course of pregnancy (Solomon

& George, 1996). Although attachment theorists use the term *attachment* to describe the child's connection "to one stronger and wiser" (i.e., the parent), many use the terms maternal-fetal attachment (Cranley, 1981) or prenatal attachment (Condon & Corkindale, 1997) to describe both the behavioral and representational components of the mother's emerging relationship to her child (Slade, Cohen, Sadler, & Miller, 2009).

Ammaniti and colleagues (1992) provide a theoretical exploration of how maternal representations are structured during pregnancy. They propose that first the representation of the infant is imaginary, as there isn't any palpable contribution from the child other than morning sickness. The representation of the child is comprised of both conscious and unconscious contributions that are influenced by the mother's personal history and present life with her significant other. The authors cite Lumley's (1982) work, which illuminates pregnant women's growing identification with their baby throughout pregnancy. The first three months are described as surreal, the women had difficulty imagining their own fetus – only 30% considered the baby a person. However, that changed over the next two trimesters. At the end of the second trimester 63% considered the baby a person and 92% did so by the 36th week.

Thus far, the research presented on the development of maternal representations during pregnancy has emphasized a deep transformation that occurs throughout pregnancy and birth; however, it is important to note that other researchers have found stability in the mother's prenatal representations of her unborn child. For instance, maternal perceptions of infant temperament during pregnancy appear to be modestly predictive of their perceptions of infants at four to six months of age (Zeanah, Benoit, Hirshberg, Barton, & Regan, 1994). Ammaniti and colleagues (1992) proposed that one

way of understanding this discrepancy is by conceptualizing two interrelated processes: one dealing with the content of the internal representations and the other dealing with how these representations are actually organized consciously and subconsciously. In their study of 23 middle class pregnant women, they explored how maternal representations are structured by the seventh month of pregnancy. The women participated in a semi-structured interview in their third trimester of pregnancy. Analysis of the interview was focused on the content. The following seven dimensions were used: richness of perception, openness to change, intensity of involvement, coherence, differentiation, social dependence, and immersion in fantasy. During the interview, the women were also given five adjective lists and asked to indicate perceived characteristics of themselves, their unborn infant, and of the infant's father. The adjective lists were conceptualized as a means of accessing content characteristics of representations, while the semi-structured interview was believed to elicit dimensions of the mother's representation of herself as a mother, and representation of her infant.

Results from the semi-structured interviews indicated similarities in the quality of representations of the mother as self and infant, the only exception to this tendency was social dependence. Interestingly social dependence was inversely correlated with openness to change. The authors proposed that women who were socially dependent (representations depend primarily on the opinions of others and upon membership within a social network) may be influenced by how the social group perceives motherhood and infant development than less socially dependent women, and they may be less likely to see their own infant clearly and less open to altering representations of their infant.

Results from the adjective list task indicated that women developed a rich representation of both themselves as mothers and their infants. For instance, during this task the women's ratings showed marked individual differences, only 8% of the ratings they made of themselves and those they made for their children correlated. The authors proposed that these findings were an indication that the women perceived their children as distinctly different from themselves. In general, these results support the notion that a complex representational network emerges during pregnancy as the mother's sense of self and her representation of the baby are evolving. However, it would be interesting to investigate the generalizability of these findings to mothers of different social-economic status, as mothers in this study were middle class, and thus may have had more resources to support individuating to their infants than mothers with less social and economic resources.

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Prematurity and the NICU as a Context for the

Emerging Mother-Child Relationship

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At this time limited research exists on how maternal representations are affected by premature birth. However, premature birth has been recognized as a risk to the quality of the parent-child relationship. Families encounter many challenges in this atypical context. First, the mothers' experience of having a pregnancy cut short and the feelings that may engender may increase the risk for maternal depression and anxiety (Davis, Edwards, Mohay, & Wollin, 2003; Singer et al., 1999). Second, the premature infant presents with his or her own vulnerabilities as he struggles to achieve physiological homeostasis and readiness to interact with the environment. Third, the NICU environment impacts the infant's neurodevelopment, the parent's accessibility to the

hospitalized newborn, the parent's sense of competence as a parent, and ultimately the parent-child relationship.

Impact of Prematurity on Mothers' Mental Health and Internal Representation of Self as Mother

Pregnancy has been considered a preparation for motherhood, a marker in a woman's life as well as an identity process (Rubin, 1975). During pregnancy a dramatic organization begins to take place at all levels: physiological, biological, cognitive, and emotional. When a pregnancy does not go as expected and is determined to be "at risk," women may need to be placed on bed rest and even hospitalized. These experiences can lead to a sense of boredom, loneliness, and powerlessness (Merkatz, Budd, & Merkatz, 1978). During hospitalization, women may feel concerned about their infants' survival, their own health, and other children at home (Loos & Julius, 1988). Further, both parents may experience emotional responses throughout the high-risk pregnancy: (1) vulnerability – the realization that pregnancy outcome was at risk; (2) heightened anxiety – the transition from normal activities to bed rest and hospitalization, and (3) inevitability – the imminent premature delivery of an infant with a guarded prognosis (McCain & Deatrick, 1994).

When pregnancy is interrupted and an infant is born prematurely, the mother is likely to experience a host of psychological challenges such as guilt, anxiety, or depression (Maloni, Kane, Suenm, & Wang, 2002); symptoms of post-traumatic stress disorder (DeMier et al., 2000); anger, helplessness, hopelessness, terror, and ambivalence about the baby's survival (Easterbrooks, 1988). Although the impact of preterm birth on the mother's emotional well-being may vary as a result of her child's medical status,

developmental outcome and age (Singer, Salvator, Guo, Collin, Lilien, & Baley, 1999), it seems that the stress and uncertainty surrounding premature birth increases the need in most mothers for social support (Davis et al., 2003; Easterbrooks, 1988; Lau & Morse, 2001). Support during NICU hospitalization, not only influences the mother's state of mind, but can influence her sense of success as a mother during breastfeeding and other caregiving tasks (Crnic et al., 1983; Crnic, Greenberg, & Slough, 1986; Flacking, Ewald, Nyqvist, & Starrin, 2005). Further, nursing staff may have a powerful impact on mothers during this time. However, nursing support can be either positive or negative. For instance, nurses can provide mothers with information about their child and can encourage and support mothers during caregiving tasks and give them with an opportunity to voice their concerns. They can also provide information in a manner that is difficult for the family to understand, provide limited scaffolding during caregiving tasks, or judge mothers as being "bad" or "incompetent." Higher levels of maternal education and increased maternal perception of social support from the nursing staff can decrease depressive symptoms (Davis et al., 2003). In general, people seem to differ in terms of the type of support they find helpful. However, even simple measures such as providing information with compassion can greatly ease the parents' emotional experience in the NICU (Dyer, 2005).

Although support is what parents need when their child is hospitalized, interactions with the medical team can hamper or enhance a mother's ability to take care of her child and herself while in the NICU. Using a grounded theory approach, Fenwick, Barclay, and Schmied (2001) interviewed 28 Australian mothers of preterm infants whose infants had been hospitalized in the NICU. They found that nurses either

facilitated or interfered with the early parent-child relationship. Inhibitive interactions with nurses caused the mothers to feel disaffection, control, intimidation, punishment, and a sense of disenfranchisement as mothers. In contrast, "chatting" with the nurses assisted parents in gaining the confidence they needed to care for their infants.

The evidence of power struggles between parents and nurses was further assessed through Lupton and Fenwick's (2001) interviews of 31 mothers of hospitalized newborns and 20 neonatal nurses in two Australian NICUs. The data indicated that nurses and mothers had different perceptions of what makes a good mother in the context of the NICU. Mothers thought it was most important to have physical contact and to breastfeed, while nurses thought it was most important for mothers to be physically present and ready to learn about the infant's medical status. Nurses felt that they were the mothers' teachers and mentors, while mothers, particularly new mothers, often experienced the nurses monitoring as intrusive and even disabling. Mothers felt they needed to ask permission to touch or hold their infants, and that their attempts at feeding felt like an examination. Further, new mothers experienced the prolonged physical separation from their babies as disabling to their sense of being a mother, while experienced mothers possessed knowledge and confidence in caring for infants as they had already established an identity as mothers.

Although power struggles appeared to be a central feature of the NICU experience for some parents, other qualitative studies highlight how parents adapted to the unique context of parenting while in the NICU. For instance, in an ethnography of 12 American mothers (Hurst, 2001a, 2001b) found that mothers were vigilantly watching over their baby's safety and at the same time fearing being labeled by the medical team as a

"difficult mother." The women's actions in the NICU were characterized by the following themes: (1) negotiating action with health care providers; (2) judicious use of challenging institutional authority; (3) use of institutional knowledge to challenge the institution's authority; (4) authoritative weight of peer practice; (5) seeking a higher authority; (6) building supportive relationships with other mothers in the NICU; and (7) garnering support from spouse/partners, families, and friends.

Further, it seems that for some mothers gaining ownership of their infants evolved during the NICU stay. For instance, Heerman, Wilson, and Wilhelm (2005) describe the experiences of 15 mothers who progressively developed from outsider to engaged parent, this process included: (1) focus from NICU to baby; (2) ownership from their baby to my baby; (3) caregiving: from passive to active; and (4) voice: from silence to advocacy. A similar process was echoed by Jackson and colleagues' (2003) phenomenological analysis of the experience of seven sets of parents of preterm infants entitled "from alienation to familiarity" and Flacking and colleagues' (2005) work about building trusting bonds while "becoming a mother" in the NICU.

These studies support the strong desire of many mothers to be close to their babies, their adaptive capacity, and the numerous obstacles parents face in trying to care for and protect their babies in the NICU. It seems that interactions with the medical team have the power to be supportive of the mother's representation of herself as a mother and her ability to care for her infant in this context or disabling. In addition to the mothers' challenges in this context, preterm infants are also working through layers of obstacles.

Challenges Presented by the Preterm Infant

While the mother of the preterm infant may suffer physically and mentally after a premature delivery, preterm infants have their own struggles, as their bodies attempt to transition to extrauterine life. This is a tremendous task given that they have immature organs and an immature body, a task that places them at significant risk for complications with every major organ system. As a result, many preterm infants are unable to survive without specialized intensive care resulting in a prolonged physical separation between mother and infant. During their hospitalization in the neonatal intensive care unit (NICU), the infants often require the assistance of a ventilator to help them with breathing for days to weeks after birth. They may have trouble regulating their body temperature and may therefore be kept in an incubator. They may have trouble feeding by mouth and may require tube feedings. Additionally, closely monitoring the newborns' medical status requires them to be subjected to uncomfortable procedures frequently.

It is during these stressful procedures and during this vulnerable time that the infant needs his mother most in order to obtain optimal nourishment, to regulate his body and for emotional connectedness. During these times is when the mother needs to be with her infant as well to assure safe passage. In fact, mothering activities with premature babies such as breast-feeding, diaper changes, and other caretaking responsibilities have been associated with positive effects on maternal well-being (Affleck, Tennen, & Rowe, 1991), increased ownership of the baby (Heermann et al., 2005), and closeness with the baby (Nystrom & Axelsson, 2002). However, many parents feel overwhelmed by the sights and sounds of the NICU as well as by the appearance of their infant (Heermann et al., 2005; Jackson et al., 2003). Depending on

the degree of prematurity, the infant's physical appearance may be greatly impacted. For instance, his size may be smaller in length, his body may appear gaunt, and his skin may be translucent. Further, other body parts such as breast buds, skin creases, and ear cartilage may not have fully developed. Additionally, the infant may be connected to a ventilator and other equipment in order to assist in survival. As a result, mothers may feel uncomfortable touching their babies, and in some cases mothers may not be allowed to hold their babies. Lastly, given the extensive transition that preterm infants must undergo to adjust to extrauterine life, they often have limited physical availability to remain in an alert state in order to interact with their parents through eye contact, feeding, and gaze holding (Als, 1982).

The NICU Environment

The NICU environment and staff can also pose a risk to the development of the parent-child relationship. The environment itself exists in order to sustain life. Therefore, not only are the infants connected to machines and placed in incubators, but the unit contains many infants in the same room with machines beeping, medications and procedures being administered, and staff members monitoring.

The incubator imposes a stark physical separation between mothers and their infants. Additionally, the traditional structure of the NICU further separates infants from their families as the system is built on an authoritarian medical model, with physicians in charge of making decisions regarding the infant's life in the hospital.

> Although families have an ultimate responsibility of long duration and broad scope for their child…the NICU's main job is to treat the baby for his primary medical problems and to discharge the infant as soon as possible…The NICU's tie to the infant, then, is of a relatively short duration…While the infant is in the NICU's custody, it is the NICU staff members, and not the parents, who make the

decisions. The NICU's job includes both medical care and the non-medical special care that flows from the child's medical needs (e.g., special feeding protocols). Some of this care can be done by non-specialists such as parents, but the NICU personal are the ones who decide who will participate and how in caring for their patient…Many decisions about the patient's course of treatment…flow almost mechanically from standards of care that mandate particular treatments for particular problems, with important modifications and adjustments to take account of the patient's reactions to interventions. (Heimer & Staffen, 1998, pp. 146-147)

Unfortunately, the traditional model of care in the NICU leaves the medical team little time or opportunity to focus on the infant's family.

Separation of the infant and his mother is a traumatic experience for both individuals. The infant needs his mother in order to obtain optimal nourishment, to regulate his body, and for emotional connectedness. These needs are magnified in a stressful environment where he is often exposed to uncomfortable medical procedures in addition to a suboptimal environment for sleep and neurodevelopment. In fact, a mother's body is the infant's natural environment – he was made to survive in coexistence with her body.

Unfortunately, mothers often have limited opportunities to engage in taking care of their infants in the NICU. Further, a mother may have to cope with many other challenges in order to get to the NICU, such as negotiating transportation issues and child care (if she has other children). When she visits the NICU, she experiences the science of caring for premature infants, rather than mother care. Learning how to care for her own infant through her own trial and error experiences with her child is not a NICU priority. She may watch nurses and other NICU staff manage her infant in a way that may not be intuitive to her.

In fact, the instinctive desire to provide the infant with safety and nourishment are well-documented universal parenting goals (Levine, 1974). All of these experiences can take a significant toll on the mother's identity as a "good enough" mother, and her image of herself as a caregiver. In this context in particular, the mother is in need of a "holding environment" to support her so she can negotiate the demands of the NICU and find ways to support her infant throughout his stay.

Lastly, nurses and other medical personnel can have a strong impact in helping a mother to feel welcome in the nursery (Lupton & Fenwick, 2001; Wigert, Johansson, & Berg, 2006). The process of mothering is essential to maternal role attainment and is strongly dependent on a woman's interactions with her infant in a social environment (Rubin, Owens, & Golden, 1998). However, even the process of mother-infant interaction looks different because many premature infants are not neurologically mature enough to sustain eye contact or prolonged social engagement. Additionally, the foreign NICU environment, which embodies advances in medical technology, may further contribute to a woman's feelings of inadequacy or disconnectedness from her infant.

Components of Parent-Infant Relationships Within the NICU

External component. The external component of the parent child relationship is comprised of behavioral interaction. The description of the NICU context highlights the challenges that the emerging parent-child dyad encounters. As a result of these challenges the behavioral repertoire is significantly impacted, as the baby is limited in terms of the range of interactive behaviors he may be able to provide. Further, his energy and stability for social interaction may be impacted as well. Parents are also restricted in the number of caregiving behaviors they may engage in. As the parents' availability for

caregiving may be impacted by comfort level and acceptance of a medically compromised child and the parents' availability to visit the hospital and receive special training to care for the baby during the many uncomfortable and often painful procedures he must encounter. Lastly, the NICU environment itself may challenge the amount and quality of interaction that occurs between parent and child. For instance, the NICU may be so noisy that the infant is overstimulated and thus unable to engage in social interaction with his parents (Johnson, 2008). The parents may not receive adequate training and feedback from the nursing staff or they may not receive clear information from the medical team, thus impacting their ability to interact effectively with the infant (Fenwick, 2001; Hurst, 2001a, 2001b).

Social interaction between infants and their parents require that both partners provide a range of communicative behavior and respond to each other appropriately. Preterm infants need additional support in order to encourage social interaction. By reading the infants' behavioral cues of organized or disorganized behavior and by observing how the environment is impacting the infant, the parent may assist the infant in neurobehavioral organization and thus facilitate infant attention for social interaction, feeding, or sleeping (Als, Gilkerson, Duffy, McAnulty, & Buehler, 2003). However, such a fine-grained analysis of subtle infant behavioral communication may not be intuitive for parents without additional training and support. Further, such optimal interaction may be especially difficult for families with multiple risk factors (e.g., low income, limited education, mental health challenges, and multiple children to support).

To date, few studies have addressed parent-child interaction within the NICU. In one recent study, Italian researchers Coppola and Cassibba (2010) investigated social

behaviors of 20 mothers of preterm infants who were in the NICU and three months after

discharge in order to verify whether these early behaviors predicted later emotional

availability. The researchers also examined the predictive value of the mothers' security

of attachment to their own parents and their reaction to the premature birth and to their

preterm infant in the hospital. During hospitalization parent-child interaction was

videotaped at three time points and later divided into two different categories: gaze

direction and communicative behavior. When the infant was three months old, mothers

were videotaped playing with their infants during a home visit. Videos were coded using

the Emotional Availability Scales (EAS; Biringen, Robinson, & Emde, 2000). Results

indicated that mothers smiling to their baby in the NICU at 30 days of life significantly

predicted later maternal sensitivity in interaction with their three-month old infants.

Additionally, the mothers' security of attachment to their own parent (measured via the

AAI) was associated with how long they spoke to and looked at their hospitalized infant.

Further, maternal behavior in the NICU was associated with the degree of prematurity

and the way in which mothers experienced the premature birth. For instance, the severity

of the infant's illness affected how mothers behaved at birth (e.g., inspecting baby vs.

gazing). Also, during the infant's stay in the NICU, mothers with very ill infants

exhibited less vocalizing and reduced facial expression directed towards their babies.

Studies after discharge from the NICU have indicated conflicting results: some

findings indicated no group differences between parents of premature infants and parents

of full term infants, while other studies indicated that mothers of premature infants are

more controlling, directive and less affectionate. Several explanations have been

postulated, including: limited infant contributions to social interaction necessitate

mothers to be more directive and supportive in their interaction style and the increased incidence of depression, anxiety and posttraumatic stress for parents of preterm infants may result in more controlling, anxious and less affectionate interaction.

While some attachment studies of premature infants and their parents have shown that preterm infants are just as likely to develop secure relationships with their parents as full term infants (Easterbrooks, 1989) and that mothers of preterm infants are just as likely to develop secure representations of their child as mothers of full term infants (Korja, 2010). Because many studies have found group differences at six months of age (Schmucker et al., 2005) but no group differences at 18 (Muller-Nix et al., 2004), or 24 months of age (Greenberg & Crnic, 1988), it seems plausible that group differences are minimized over time as the infants mature and perhaps as mothers recover from the stress of complicated delivery and the baby's early life experiences.

Other researchers have found that mothers of preterm infants provide their infants with extra supports such as vocalization, face-to-face contact, and touch in order to cue the infant to attend. However, mothers also demonstrated less warmth characterized by lower affect and less smiling and affectionate physical contact (DiVitto & Goldberg, 1979; Minde, Perrotta, & Marton, 1985; Schmucker et al., 2005). Mothers of preterm infants tended to interact with their children more often than mothers of full term infants (Greenberg & Crnic, 1988) and their interactions appeared more structured and controlling (Gerner, 1999; Muller-Nix et al., 2004). Additionally, differences in maternal behavior were most evident during the infant's first three months of life (Minde et al., 1985) but persisted for up to two years (Minde, 2000).

Forcada-Guex et al. (2006) found that 28% of the preterm-mother dyads demonstrated a "controlling pattern," characterized by maternal controlling behavior and the infant demonstrating compulsive-compliant behavior. In contrast, only 12% of the full-term group demonstrated the controlling pattern. Another 28% of the preterm dyads demonstrated a "cooperative pattern," characterized by sensitive maternal behavior and cooperative-responsive infant behavior; 68% of the full term dyads demonstrated this pattern of behavior.   Further, the outcomes of the controlling dyads indicated that infants whose mothers demonstrated the "controlling pattern" were at risk for a host of challenges at 18 months including behavior problems, eating problems, and lower social and communication skills.

Based on the above studies, it seems that infant risk factors impact maternal interaction factors. Muller-Nix et al. (2004) further examined the role of extreme stress or trauma, infant perinatal risk factors and the quality of mother-infant interaction at six and 18 months (corrected for gestational age). Results indicated that the infant's severity of risk impacted the quality of interaction at six months of age but not at 18 months. Next, the impact of maternal stress on parent-child interaction was measured with the administration of the Post-traumatic Stress Disorder Questionnaire (PPQ) and then by dividing the subjects into premature high stress, premature low stress, and full term groups. Parent child interaction was measured via the Care Index (Crittenden, 1988) which provided codes for both the parent's and the child's contribution. Results indicated that maternal stress impacted maternal sensitivity and controlling behavior when the infants were six months old. However, there were no significant group differences when the infants were 18 months old. Further, although the infants

demonstrated insignificant differences in parent-child interaction at six months, by 18 months the infants in the premature high stress group exhibited a higher rate of compliance-compulsivity and passivity. The authors point out that a relationship between controlling maternal behavior and compliant child behavior has already been demonstrated in the literature (Crittenden, 1988). These findings indicate that there may be a long lasting interactional effect of maternal trauma during the perinatal period on parent-child interaction and that the influence may not be seen in infant behavior until 18 moths. Further analysis indicated that maternal traumatic experience as measured by the PPQ represented a mediating factor for maternal interaction at six months of age.

Internal component. Only four studies of maternal attachment representations in preterm infants and their mothers exist (Borghini et al., 2006; Korja et al., 2010; Korja et al., 2009; Meijssen et al., 2011). None of these studies examined maternal representations during high-risk pregnancy or while preterm infants were in the NICU. Rather, the studies examined maternal representations of preterm infants when the infants were 6, 12, or 18 months (post gestational age). Borghini et al. (2006) found that only 20% of mothers of premature babies had secure (balanced) attachment representations when the children were 18 months vs. 53% of the control group (mothers of full term, uncomplicated infants). In contrast, Meijssen et al. (2011) also studied an Italian population from a similar demographic and found that 70% of mothers of premature babies had secure (balanced) attachment representations when the children were 18 months of age, they did not have a control group of full term infants as the study's purpose was to evaluate intervention. Thirty percent of the mothers demonstrated non-balanced attachment representations. Qualitative content analysis of select questions that

may be specific to prematurity on the WMCI indicated that negative feelings when first seeing their baby and negative or ambivalent feelings in the first few weeks at home were related to non-balanced attachment representations.

In another study, Korja (2009) assessed attachment representations when of the Child Interview (WMCI). However, Korja found that maternal infants were 12 months adjusted age and did not find any differences between groups in terms of distribution of the three main representation categories on the Working Model depression symptoms were associated with the distorted representation category. Korja et al. (2010) then considered the relationship between maternal attachment representations (assessed via WMCI) and the quality of mother infant interaction (assessed via the Parent Child Early Relational Assessment – [PCERA]) in preterm and full-term infants. Results indicated that WMCI representation categories were related to six out of seven PCERA scales in the preterm infant group and five out of seven PCERA scales in the full-term group.

These results appear inconclusive: Borghini et al.'s (2006) study found group differences in secure attachment, while Korja (2009) did not. One important note is that Borghini et al.'s premature group came from a lower socioeconomic stratum than the control group. Lower socioeconomic status can increase the risk for problems in the mother-child relationship (Wille, 1991). Additionally, Korja et al.'s studies (2009, 2010) were conducted in a Finnish hospital where, by the researchers' disclosure, the high proportion of the mothers' balanced attachment representations and the good quality of mother infant interaction in the preterm group may be related to the degree of parent support received in the NICU, parent's active involvement in the infants' care during the NICU period, and the incorporation of daily skin-to-skin contact (kangaroo care) between

mother and preterm infant. It has been documented that kangaroo care may facilitate maternal sensitivity as the close physical contact can help mothers learn their preterm infant's cues and take an active role in infant care (Feldman, Weller, Sirota, & Eidelman, 2003). It should also be noted that all four studies were conducted in European countries, where family leave policies are more generous and child care arrangements (to care for additional children while the mother is in the hospital with an ill newborn) are more supportive than those in the United States.

Conclusion

In summary, maternal representations or internal working models are a useful port of entry for understanding early parent-child relationships. Internal working models have evolved from Bowlby's attachment theory and relate to one's ability to seek support and provide comfort within the context of relationships, to interpret another's intentions and responses, and to value one's sense of self. Parents' internal working models are thought to guide parenting behaviors, which in turn shape the security of the child's attachment to the parent. For a young child with limited experience of the world, his perception of the world is completely tied to his experience in his relationships with caregivers. When caregivers are unavailable, abusive, or inconsistent, the child understands this behavior as a reflection of himself. For instance, he may assume that the parent is behaving negatively because he is inherently bad, too demanding, or not worthy of love and support. If these patterns persist, the child is likely to develop a negative view of himself, and thus the stage may be set for difficulties with later relationships. Although empirical research has not directly linked a list of causal factors to the development of internal representations, it seems likely that a mother's internal working models are influenced by

the quality of her relationships both past and present, her mental health, support systems, reflective function, and her infant's temperament.

Another challenge, which may impact a mother's internal representation, is that of a high-risk pregnancy, premature delivery, and subsequent newborn hospitalization in the NICU. At this time there is an absence of research on maternal internal representations of their newborn preterm infants. We understand that prenatal attachment deepens throughout pregnancy (Berryman & Windridge, 1996; Bloom, 1995; Wayland & Tate, 1993), particularly as one completes the second trimester and the first fetal movements are felt (Klaus & Klaus, 1985). We also know that gestational weeks 24-32 are a crucial period for the development of maternal representations (Ammaniti et al., 1992), as women have developed a clear representation of themselves as mothers, distinct from their fetus. Premature delivery interrupts a women's internal representation development of the child and of herself as mother. Therefore, the mother's mental representation of the infant and the real preterm infant often differ (Stern et al., 1998). Further, as a result of the infant's critically ill state, parents may be placed in an "impossible situation in which they cannot elaborate a meaningful representation structure of the future. They are in a representational vacuum – when you cannot imagine the future, you cannot evaluate the present" (Stern, 1995, p. 39).

Moreover, the lack of intimate contact between parents and their infants in the NICU, along with the protocol-based care, prevents parents from making decisions regarding virtually all routine caretaking tasks, such as feeding times, manner of feeding, diaper changes, and so forth. Once infants are discharged home from the NICU, parents are able to take over ownership of their infant. Nevertheless, infants may continue to

have difficulty being physically available for interaction or they may have difficulty with self-regulation (Wolf, Koldewijn, Beelan, Hedlund, & deGroot, 2002). Parents may continue showing increased anxiety and limited confidence in their caregiving abilities throughout the first year of life (Crnic et. al., 1983; Corter & Minde, 1987). Studies on parent-child interaction indicate conflicting results; some show mothers as intrusive, providing excessive stimulation to their preterm infants (Miles & Holditch-Davis, 1995), while others describe mothers' behavior toward their infants as adaptive and necessary (Goldberg & DiVitto, 1995).

In terms of mothers' internal representations of their preterm infants, the results are inconclusive. Borghini et al. (2006) found an increased incidence of insecure attachment, while Korja (2009) did not. However, they found maternal depression to be associated with distorted maternal representations of the child. Furthermore, at this time there is an absence of research on the quality of maternal representations of infants hospitalized in the NICU. Given the potential risks to the early parent child relationship in the NICU context, as well as the stability of maternal attachment representations throughout the first year of life and the association between maternal representations in pregnancy and an infant's attachment security at 12 months, research on women's internal representations of their newborn preterm infants is an area that is very important to study.

CHAPTER III

METHODOLOGY

Theoretical Framework

The purpose of this study is to describe the emerging relationship between mother and preterm infant within the context of the Newborn Intensive Care Unit (NICU) using a multiple case study design with multiple methods and data sources. The study will present a portrait of each dyad's relationship in order to depict how mothers understand their relationship with their newborn, how they understand who the newborn is as a person, how they go about caring for their newborns in this context, and how the infant responds to his mother's caregiving attempts. The central concept of the internal working model will be elicited through the administration of the Working Model of the Child Interview (WMCI), consisting of semi-structured interviews with the mothers and primary care nurses and observations of the mother-infant dyads. Additionally, behavioral interaction between mother and newborn will be documented through the use of NIDCAP observation.

The NICU context is complex and comprised of many layers that influence the developing parent-child relationship. First, the physical environment imposes a tremendous barrier to physical contact given the use of life saving equipment (i.e., incubators, monitors, feeding tubes, IV lines) needed to support the newborn at this time. Further, the nurses in the NICU may empower parents to feel like they can care for their infants in this context or they may get in the way of that happening. Second, the infant is

physically ill and has limited physiological availability for social interaction. The infant

may also look different than a typical newborn, which may be disturbing for some

parents. Third, the mothers are often coping with their own feelings of loss of pregnancy,

guilt about not carrying the pregnancy to term, and fatigue from birth. Given the myriad

variables that could potentially influence the parent-child relationship in the NICU and

the mother's internal working model of her infant, her relationship with her infant, and of

herself as a mother, a case study approach utilizing multiple methods and multiple data

sources seems appropriate.

Multiple methods appear warranted as a means of microanalysis. In order to

examine how the individual and contextual variables meld together, it appears that the

individual, the context, and their relationship need to be studied (Lerner et al., 2005).

Qualitative methods such as phenomenological interviews, field notes, and observations

are important in order to learn about each woman's unique experience within this context.

Additionally, standardized instruments are useful in order to provide more detail about

the newborn's behavior, to quantify the fluctuations in the infant's health status as well as

the fluctuations of activity and stimulation within the NICU environment, and to provide

specific information regarding mother's internal working models, mental health, and

social support. My goal is to embed the mother's experience of being in a relationship

with her newborn in the NICU with other contextual variables relating to the NICU

environment, the infant, the mother's support system, and her mental health.

This case study design represents the desire to derive an in-depth understanding of

a small number of cases, set in their real world context. This approach is particularly

relevant when investigating complex social units consisting of multiple variables of

potential importance in understanding the phenomenon (Merriam, 2009). Through its careful and detailed examination of a phenomenon, case study allows for the researcher to focus on the specific context in which the phenomenon develops. It strives to produce an "insightful appreciation" of the cases – hopefully resulting in new learning about real-world behavior and its meaning (Yin, 2012). Case study research assumes that examining the context and other complex conditions related to the cases being studied are integral to understanding the cases. This in-depth focus on the cases, along with the coverage of a wider breadth of contextual conditions, will seek to offer insights and illuminate meanings that may expand the field's knowledge base. The final product of the case study design will produce a "thick description" of context and will emerge from multiple not singular sources of evidence (Stake, 1995a).

While authoritative sources such as the U.S. Government Accountability Office (1990) and others (Yin, 1992, 1994, 1997) have documented the many applications of the case study method, the issue of generalizability looms larger within this approach than with other types of qualitative research. However, case study design is not chosen in order to optimize production of generalizations, but it may produce a modification to an existing generalization (Stake, 1995b). In fact, "the real business of case study is particularization, not generalization" (p. 8). Yin (2009) describes two types of generalizing: statistical generalizations and analytic generalizations. Case studies provide analytic generalizations as they depend on using a study's theoretical framework to establish a logic that might be applicable to their situations. He proposes that both types of generalizations adhere to the same two-step process. First, a conceptual claim is made through which researchers show that the study's findings have informed the relationships

among a particular set of concepts, theoretical constructs, or sequence of events. Second, these theoretical propositions are applied in order to "implicate other situations, outside the completed case study, where similar concepts, constructs or sequences might be relevant" (p. 38). Therefore, "case studies tend to generalize to situations (on the basis of analytic claims), whereas surveys and other quantitative methods tend to generalize to populations (on the basis of statistical claims)" (p. 39).

Description of the Case

The mother-infant relationship in the context of the NICU was explored as the unit of analysis. Although fathers as well as other caregivers can be studied within the context of attachment theory and the caregiving system, I decided to focus this study on mothers for two reasons. First, mothers remain the most common primary caregivers of infants. Second, most previous research on internal working models has focused on mothers. Therefore I would first like to extend previous research on maternal internal working models to the context of the NICU, and then study fathers in this context as part of a separate study in the future.

This study is a depiction of the mother-child relationship within the atypical environment of the NICU. I am particularly interested in learning about women whose infants are premature; therefore, inclusion criteria will be based on infant and maternal characteristics. Five mothers were recruited whose infants were born up to 32 weeks gestation. My goal was to obtain a sample of infants that would remain within the NICU for at least one month. Exclusion factors included: infants with severe congenital abnormalities, multiples (i.e., twins, triplets), maternal drug use, and severe maternal physical or mental illness. Further, as language capacity is vital for the interview

method, only mothers who were fluent speakers of English were asked to participate in the study. A severe congenital anomaly may present additional challenges to the parent, particularly relating to a potentially short life span, lifelong medical complications and significantly limited developmental outcomes. Women who have multiple infants may also have a different set of challenges and perhaps different internal working models for each infant. Although this topic is interesting, it is beyond the scope of this study. Maternal drug use and severe physical and mental illness also present with additional challenges that may provide unnecessary "noise" in studying internal working models and parenting in the NICU.

Research Questions

1. What are mothers' internal working models of their preterm newborns?

2. What is the behavioral interaction like between mothers and their preterm newborn and how is it impacted by the infant's medical status and the mother's mental state?

3. What are the preterm infants' capacities for social interaction with their mothers? How does the infants' capacity for interaction impact the mother's understanding of herself as a mother and her representation of her infant?

4. What is the experience of mothers in the NICU environment? How does each mother's NICU experience impact her understanding of herself as a mother and the mother's representation of her infant?

Description of the Context

The study was conducted in the Newborn Intensive Care Unit at "Midwest" Medical Center in Chicago. Midwest NICU is considered a Level III center, meaning that the NICU has been given the highest level of intensive care designation (awarded by

the state of Illinois) for premature and critically ill newborns and is a regional referral

center. The unit contains 50 beds, 30 of which are designated for acutely ill newborns.

Each year the hospital's NICU cares for 900 critically ill infants. The hospital is

positioned in a western suburb of Chicago and serves a socioeconomically and ethnically

diverse demographic, offering health care to the traditionally medically underserved,

public aid patients, insurance patients, as well as self-pays.

Instrumentation

The study used multiple methods and data sources, including interviews with

mothers, surveys completed by mothers, observation of the mother with her newborn

infant, observation of the NICU environment, and infant health status qualification.

Mothers' Internal Working Model of the Child

The Working Model of the Child Interview – (WMCI; Zeanah et al., 1994) was

used to measure maternal IWMs of the newborn. The WMCI is a one-hour structured

interview that assesses a participant's perceptions and subjective experiences of her

infant and relationship with her infant. Each interview was assigned an overall

classification of the narrative. The classifications included balanced, distorted and

disengaged representations. Mothers were interviewed using the WMCI in a private

room within the NICU.

Several researchers have developed instruments to assess caregivers' internal

working models of their child, the parent-child relationship and their parenting role. For

instance the Parent Development Interview (Aber, Slade, Bresgi, & Kaplan, 1985), and

the Parental Attachment interview (Bretherton et al., 1989) were developed for this

purpose. Additionally, Stern developed an interview for use in a study of the effects of

psychotherapy on mothers' representations of their infants (Cramer & Stern, 1988). I

will focus this review on the Working Model of the Child Interview – WMCI (Zeanah et

al., 1994) as this tool has been used to study internal representations of mothers with

preterm infants (Borghini et al., 2006; Korja et al., 2010; Korja et al., 2009) as well as

pregnant mothers internal representations of their unborn infants (Benoit, Parker, &

Zeanah, 1997; Theran, Levendosky, Bogat, & Huth-Bocks, 2005).

 The WMCI systematically examines parental internal representations of their

infant – their perceptions and subjective experience of their infants' individual

characteristics and the relationship with their infant (Zeanah & Benoit, 1995). It has been

correlated with the child's behavior in the Strange Situation and with mother-child

interactive behavior (Benoit et al., 1997; Zeanah & Barton, 1989; Zeanah et al., 1994).

Further, the WMCI has been strongly influenced by the Adult Attachment Interview

(AAI).

 During the hour-long interview parents are asked to describe their emotional

reactions during the pregnancy, to describe their infant's personality, the characteristics

of their relationship with their infant, to elaborate on any perceived or anticipated

challenges they face with the infant, and their reactions to their infant's distress in a

variety of contexts. Responses are recorded and the narrative features of the interview

are analyzed. Based on the quality of the narrative the caregiver's representations are

placed into one of three categories: balanced, disengaged and distorted – which have been

noted to overlap with the three AAI categories (secure/autonomous, dismissing,

preoccupied) and the three Strange Situation Procedure categories (secure, insecure

avoidant, insecure resistant-ambivalent).

A *balanced* representation is characterized by descriptions of both negative and positive characteristics of the infant and the relationship with the infant are provided. Caregivers have moderate to high scores on the coherence scale – the narrative is well organized and the flow of ideas and feelings about the infant and the relationship is understandable. Further, the caregiver is psychologically invested, even engrossed in the relationship – the infant's individuality is valued and the caregiver's relationship with the infant is growing and open to change and the caregiver empathically appreciates the infant's subjective experience. *Disengaged* refers to a pervasive sense of coolness or emotional distance towards the infant. The infant's subjective experience seems alien to the caregiver, as if she did not know the infant as an individual. The caregiver's relationship with the infant can be approached on a cognitive level, remote from feelings and emotions. The caregiver's narrative lacks richness about the infant or parenting experience and may also lack flexibility to accommodate to changes or new information about the infant. *Distorted* narratives are inconsistent. For example, the caregiver may seem preoccupied or distracted by other concerns, confused and anxiously overwhelmed by the infant. Although the caregiver often expresses a lot of emotion during the interview, these emotions lack modulation and contextual meaning within the context of the interview about the child and the parent-child relationship. The caregiver may be self-involved or may expect the infant to please the parent or to behave in an excessively compliant manner. Malevolent intentions are attributed to the infant or are grossly insensitive to the infant as an individual. Parents who have distorted internal representations rarely recognize the impact their parenting may have on their infant. Contrary to the disengaged group, the distorted group does not dismiss parenting

experiences, they simply fail to recognize fully the detrimental impact their parenting

may have on the infant. Furthermore, distorted parents may demonstrate grossly

inappropriate parenting such as role-reversal.

The stability and predictive validity of the WMCI has been examined in several

studies. In a sample of 45 middle class mothers living in the United States and their one

year old infants, the WMCI classifications were systematically related to their infants'

concurrently assessed attachment classifications at age 12 months (Zeanah et al., 1994).

The relationships between mothers' narratives as balanced and infant attachment

classification as secure and between distorted maternal narratives and infant resistant

classification were particularly strong.

Benoit et al. (1997) replicated and extended these findings to include a sample of

pregnant, middle class Canadian sample of 85 mothers and infants. Concordance was

assessed for both the WMCI codes during pregnancy and one year postpartum and for the

WMCI codes during pregnancy and infant SS classifications at one year of age. Findings

indicated that the WMCI ratings were stable over 12 months in 80% of the mothers.

Further pregnancy WMCI ratings predicted infant SS classifications in 74% of the cases.

Concordance between the 11-month WMCI ratings and the infant SS classifications at 12

months was 73%. In fact, 91% of mothers who were classified as balanced had infants

classified as secure in the SS.   Further, Benoit et al.'s findings not only support the

stability of the WMCI as an instrument, but they also support the stability of maternal

representations during pregnancy as well as their impact on infant attachment

classification when the infant is one year of age.

Mothers' Experience of Preterm Birth, Having a Premature Baby, and Parenting in the NICU

Three interviews were conducted and followed a modified version of Seidman's (2006) structure of in-depth, phenomenological interviewing. This method combines life-history interviewing and focused, in-depth interviewing informed by assumptions drawn from phenomenology. In this type of interview, the mothers are presented with open-ended questions. The interviewer's major task is to build upon and explore the participants' responses to those questions. The goal is to have the participant reconstruct his or her experience within the topic of interest. Seidman advocates for conducting three separate interviews with each participant as this form of interviewing allows behavior to become meaningful when placed in the context of their lives and the lives of those around them. The goal of the first interview is to establish the context for the participants' experience. The second allows participants to reconstruct the details of their experience within the context in which it occurs. And the third encourages the participants to reflect on the meaning their experience holds for them.

a) *Interview #1 = Focused history.* The purpose of the first interview was to establish rapport, obtain a sense of history regarding the mother-baby relationship, and examine the pregnancy, labor and delivery. The participants were given the first section of the Working Model of the Child Interview (WMCI; Zeanah et al., 1994), which pertained to the pregnancy, labor, and delivery and the time shortly after birth.

b) *Interview #2 = Details of the experience.* The second interview focused on the completion of the WMCI.

c) *Interview #3 = Reflection on meaning.* The final interview took place as the infant is

approaching discharge. The focus of the interview was to reflect on the participant's

experience of becoming a parent to a preterm baby, as well as their lived experience

as a parent caring for their child in the NICU.

Behavioral Interaction Between Mothers and their Newborn Infants

In order to create an in-depth case study, I conducted detailed observations of the

mother and infant, during feeding and or diapering activities. The newborn's behavior

was coded via neurobehavioral, NIDCAP (Newborn Individualized Developmental Care

Assessment Program) observation (Als, 2009; Als et al., 2003) in order to highlight the

infant's function of all subsystems (autonomic, motor, state, interaction) and how these

systems interact during this interaction with his mother. Within the NIDCAP framework,

each of these subsystems provide information regarding each infant's unique ability to

manage the stress of a given caregiving interaction as well as his attempts to

communicate his needs to his caregiver. The mother's contribution to caregiving was

noted through her ability to notice and respond contingently to the infant's

communicative attempts.

My training in the NIDCAP framework was completed over a one and a half year

time span at the University of Illinois Medical Center, a recognized NIDCAP Training

Center. During this time I achieved NIDCAP certification, which recognized my ability

to conduct reliable neurobehavioral observations of both the infant and his caregiver, and

to provide appropriate support to caregivers in order to assist them in recognizing and

respond supportively to the infant's communicative signals. Additionally, my training as

a licensed pediatric speech-language pathologist and feeding specialist has provided me

with a rich understanding of the skills needed to be able to safely eat by mouth. For instance, swallowing skills are broken down into three phases: oral preparatory, oral transit, and pharyngeal phases. The oral preparatory phase for feeding by bottle or breast would relate to the infant's ability to extract fluid from a bottle or breast, oral transit refers to the infant's ability to safely transport the liquid from the front of the mouth to the pharynx (back of the mouth), and the pharyngeal phase refers to the initiation of the swallow response at the back of the throat, for the liquid to transport from the back of the throat to the esophagus rather than the trachea. My background as a feeding specialist will further enhance my understanding of the infant's needs during feeding.

Through this microanalytic infant NIDCAP observation, I hope to learn what the infant needs in a given situation and how to optimize the infant's experience, limit his distress, and encourage his physical and emotional availability for social interaction. The purpose of this observation will be to focus on the mother's attempts to both observe and support her infant's needs and to document the infant's capacity for participation in social interaction, feeding and other caregiving activities.

NICU Environment

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Environment Template (Als, 2009; Als et al., 2003) has been used in research to assess the NICU environment, specifically the organizational structures supporting the physical environment (Als et al., 2003). The NIDCAP Environment Template evaluates aspects of the environment using a five-point rating scale. Ratings are performed by a trained observer who has achieved reliability in the NIDCAP methodology and has been deemed reliable by a NIDCAP trainer in the use of this measure.

Two out of three sections of this measure were used for the purposes of this study: Physical Environment of the Nursery and Physical Environment of the Bedspace. The Physical Environment of the Nursery assesses the location in relation to labor and delivery and the mother's postpartum room, the appearance of the nursery, physical layout in terms of how it may accommodate for family space, density and size of bedside space, design of bedside space, conduciveness for family participation, and conduciveness for professional care components. The Physical Environment of the Infant's Bedspace examines light level, sound level, activity level, visual array inside of incubator/crib space, olfactory inputs, bedding and clothing, and specific regulatory aids. It is important to note that this assessment provides a numerical value for each section component but does not provide a cumulative score for each subtest.

Infant's Health Status

The following data regarding the infant's medical course was collected via medical chart review when the infant is approaching discharge: infant birth gestational age, birth weight, Apgar scores, respiratory care provided in NICU, surgeries, and number of days the infant was hospitalized in the NICU.

Maternal Mental Health

Given the impact of mental health on maternal representations, I documented symptoms related to general distress, anxiety and depression. I used the Mini Mood and Anxiety Symptoms Questionnaire - Mini-MASQ (Casillas & Clark, 2000) to accomplish these goals. The Mini-MASQ is a 26-item, short adaptation of the 90-item Mood and Anxiety Symptoms Questionnaire (MASQ). For each item on the Mini-MASQ,

participants were asked to qualify (1 = not at all, 5 = extremely) how they have felt or experienced various emotions in the past week.

Social Support

The Norbeck Social Support Questionnaire – NSSQ (Norbeck, Lindsey, & Carrieri, 1981) assesses multiple dimensions of social support, including: emotional support, practical support (or aid), size of the social support network, duration of support and frequency of contact with supporters. All of the items are rated on a scale ranging from 0 (not at all) to 4 (a great deal).

Summary

Table 1 clarifies which data points were used in order to answer the research questions.

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Procedures

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Given that I was not a hospital employee, the Neonatology Director, Dr. M., screened the intake weekly and identified mothers and infants that met the criteria. He approached the mothers and invited them to participate in this study. I met with the mothers to provide both written and oral explanations of the study's risks and benefits. The participants were assured that all concerns of privacy and confidentiality will be appropriately addressed. For instance, the participants' names were not used on the typed transcript of the taped interview or on the completed inventory. Participants were advised that they are free to withdraw from the study at any time without penalty. Tape recordings, transcripts, and completed inventories were kept confidential.

The mothers were interviewed three times in a location of their choosing, some chose a private room in the NICU, while others preferred to hold their baby and remain at

the baby's bedside. Additionally, they were observed engaging in caregiving activities with their infant. They also completed three questionnaires: Mini-MASQ, NSSQ, and a demographic questionnaire.

Table 1. Research Questions and Data Points

RESEARCH QUESTION	DATA POINT
1. What are mothers' internal working models of their preterm newborns?	WMCI, phenomenological interviews with mothers, mother-infant observation
2. What is the quality of the behavioral interaction like between mothers and their preterm newborn and how is it impacted by the infant's medical status and the mother's mental state?	Mother-infant observation, infant health status, Mini-MASQ
3. a) What are the preterm infants' capacities for social interaction with their mothers? b) How does the infants' capacity for interaction impact the mother's understanding of herself as a mother and her representation of her infant?	a) Mother-infant observation - NIDCAP infant observation, infant medical data b) phenomenological interview with mothers c) chart review – nursing notes
4. a) What is the experience of mothers in the NICU environment? b) How does each mother's NICU experience impact her understanding of herself as a mother and her representation of her infant?	a) Phenomenological interview with mothers, observation of mother and infant, observation NICU environment b) Phenomenological interview with mothers, WMCI, Mother-infant observation

Data Analysis

The first phase of analysis involved coding and scoring all of the quantitative instruments (WMCI, NIDCAP infant observation, NIDCAP environmental observation, mini-MASQ, and the NSSQ). In order to reduce the likelihood that my interactions with

the mothers or knowledge of their performance on other measures may bias my coding, the WMCI interview was coded by WMCI co-author and trainer, Anna Smyke, PhD. Both the infant neurobehavioral observation and the NICU environment were coded according to the NIDCAP observation manual; I have achieved coding reliability for this instrument. The NSSQ and Mini-MASQ were scored according the corresponding administration instructions.

The second phase of analysis involved transcribing and coding qualitative interviews and the mother-infant observation. The interviews were analyzed and codes were created based on themes that emerged after examining the transcript as a whole, then by examining words, phrases, lines and paragraphs of the transcripts.

The final phase of analysis involved triangulating qualitative and quantitative data sources. Next, descriptive data were generated for all of the standardized assessments and a case presentation was compiled for each of the five dyads.

Ethical Considerations

Although the overall format of the interviews and observations was structured so that they were sensitive to the participant's needs, there was a possibility that the types of questions asked during the interview process may evoke feelings of uncertainty or discomfort. For instance, a study (Meijssen et. al., 2011) that researched mothers of preterm infants 18 months after birth using the WMCI found that the WMCI evoked strong emotional responses in one-third of the mothers. Although the responses including crying, guilt and difficult memories, the women felt relieved to talk about these experiences because they could not easily speak with others about these issues. As a precaution, participants were encouraged to stop the interview at any time if they feel

uncomfortable. Because the study was based in a hospital and the participants were working with their infant's medical team, counseling services were available to the participants at any time through the hospital neonatal social worker.

Validity Considerations

In order to ensure the trustworthiness of my research, I used multiple data collection methods such as interviewing the mothers, observing the mothers with their infants, observing the hospital environment, review of each infant's medical chart, and standardized assessments to quantify the mothers' mood, perception of social support, and mothers' internal working models of their infants. Additionally, collecting data from multiple sources provided a means of triangulation whereby I was able to compare the interview results with several other data sources. Lastly, in order to assure that the interviews were interpreted accurately, after the data was analyzed – I checked the interpretation with each mother.

Within qualitative research the researcher is an instrument that interprets and codes data; as such my own subjectivities may come into question, which is common to all areas of qualitative inquiry. However, subjectivity need not be seen as a failing that needs to be eliminated, but as an essential element of understanding (Stake, 1995). Subjectivity should be monitored rather than controlled, so that increases one's awareness of ways it may distort, but it is also the basis for who we are as people. Through self-awareness, one learns how one's own life history has formed a self-narrative and how that narrative may form the basis for how we filter information. Two strategies for accounting for subjectivity are keeping a researcher's journal and complete self-disclosure.

Keeping a researcher's journal is a way to document the interaction between the researcher's own bias (or positioning as a research instrument) and the events and participants in the field. The journal "will contain a record of experiences, ideas, fears, mistakes, confusions, breakthroughs, and problems that arise" (Spradley, 1979, p. 76). Therefore, during this study a journal will be kept in order to record my own impressions, through processes and experiences.

As mentioned, self-awareness is an important component of controlling for subjectivity and understanding one's own biases, beliefs, experiences and how they may influence the lens through which information is filtered. In terms of my professional background, I am a pediatric speech-language pathologist who has spent eight years working closely with children and their families who are impacted by speech, language, and feeding challenges. This work has given me the privilege of working closely with preterm infants and their parents during their stay in the NICU as well as through neonatal follow up clinics and outpatient therapy. In my personal life, I am the mother of three children ages seven, six and one. Therefore, the experience of early motherhood is not in the distant past. I must recognize that both my personal and professional experiences may bias my interview technique and the way I may interpret the information. As a researcher, I will need to work to remain open to the information I obtain throughout this study and to not allow any biases to distract me from representing the mothers' stories accurately.

Limitations

Given that the women in this study will be interviewed several times, it is possible that the opportunity to reflect during the interview may actually change how they

perceive themselves, their roles as mothers, their infants, and even the context of the NICU. This issue is one of *intersubjectivity*, as it is not only the subjectivities of the researcher that shape the research. Rather, in situations where the researcher and participant interact over a period of time, the subjectivities of all players guide the research process and content. Thus, the final product is an intersubjective co-construction of knowledge, called *ontological authenticity*. Further, ontological authenticity is one of five validity criteria intrinsic to naturalistic inquiry (Guba & Lincoln, 1989). This criterion speaks to the ability of the research project itself to make individuals aware of how they "construct" the world and make sense of phenomena. The extent to which involvement in a research project makes participants more cognizant of their own meaning making processes is a measure of the validity of the research process itself (Lincoln, 2001).

Additional limitations are consistent with case study methodology: findings may be limited to the five participants studied in the NICU at "Midwest" Medical Center. However, as I discussed above, the goal of case study research is not statistical generalization but analytic generalization. Therefore, I plan to use the study's theoretical framework (attachment theory, ecological systems model) to establish a logic that may be applicable to other parents in the NICU. Yin (2012) points out that for both case studies and experiments, the objective for generalizing the findings is the same two-step process. First, a conceptual claim is made, through which the investigators show how their findings have informed the relationships among a particular set of concepts, theoretical constructs or sequence of events. Second, the same theoretical propositions are applied to other situations, where similar concepts, constructs or sequences might be relevant.

Therefore, "case studies tend to generalize to other situations (on the basis of analytical claims), whereas surveys and other quantitative methods tend to generalize to the populations (on the basis of statistical claims)" (p. 19).

CHAPTER IV

RESULTS – INDIVIDUAL CASE ANALYSIS

Introduction

Chapters IV and V present the findings obtained from this study. This chapter will focus on individual case analysis and the next chapter will focus on analysis across all five cases. In this chapter the emphasis is on introducing the NICU context as well as the five dyads (cases): Patty/David, Cindy/Chloe, Grace/Aiden, Lindsay/Bryce, and Kara/Kiki. The initial section provides both qualitative and quantitative information regarding the NICU environment. The second section contains background data for all five cases: (1) demographic information; (2) infants' health and medical course; (3) mothers' social support and emotional well-being; and (4) mothers' internal working model of their infants. Multiple data sources were used, including surveys, questionnaires, and standardized interviews to obtain these data. The final section will focus on presentation of the qualitative data (i.e., phenomenological interviews and caregiving observations) within the format of individual case presentations.

NICU Environment

The Walk of the Family

For the purpose of anonymity, the NICU and medical center that was studied will be referred to as Midwest NICU or Midwest medical center. The NICU at Midwest is located on the fifth floor of a large medical center. In order for patients to access this unit, they must visit after 12 pm each day as the 9-12 morning hours are reserved for morning

rounds. When arriving at the Midwest medical center one must park in an adjacent parking garage and navigate through the medical center, find the appropriately marked elevators, and take the elevators to the fifth floor. Upon entering the correct floor, the family will take approximately 50 steps to approach a set of locked double doors and a glass-encased reception area. They must then knock on the window and explain to the receptionist who they are here to visit. Once granted access, the double doors will open, and they will be instructed to step to the right and to follow appropriate hand washing procedures in order to minimize the risk of exposing their newborns to infection. The families must use a surgical brush to scrub their hands and forearms with sterile soap and a pick to clean the underside of their fingernails. After completing this task and drying hands, they will be allowed access through the second set of double doors.

Upon entering the NICU, the family encounters a large single room nursery containing approximately 40 beds and a smaller room behind the large one, containing approximately 10 beds. The walls are decorated by a pastel border and softly colored wallpaper. The fluorescent lights reflect from the white tile floor and illuminate four long rows of tiny plastic beds. Natural light cascades into the unit from the back wall, which is lined with windows.

Each bed space contains a monitor, an IV pole, and a chair. Some bed spaces contain additional equipment that is necessary to keep that particular infant alive. Monitors beep loudly, the sound of conversation rises and falls as it echoes through the room, voices blare over an intercom, telephones ring, and keyboards click as health care providers type. Some parents gather next to their children's bedsides, particularly in the evening hours when most arrive from work. Parents huddle together near their child's

bed, so they do not disturb their infant's neighbor – another small infant, lying in a plastic box with his or her visiting family.

Profile of the Nursery Environment and Care Components

The *NIDCAP Profile of the Nursery Environment* (Als, Buehler, Kerr, Feinberg, & Gilkerson, 1997) was administered in order to document components of the physical environment which infants and their families experience during the course of their hospitalization in the NICU. Each characteristic is rated on a 5-point Likert rating scale; a score of 1 refers to a lack of consideration or misunderstanding of developmental opportunities, while a score of 5 reflects a high degree of developmental sensitivity. The NIDCAP Profile of the Nursery Environment has three components: physical environment of the nursery; physical environment of the infant's bed space; and specific aspects of direct infant care. For purposes of this study, the first two components were administered at the time of the mother-infant caregiving observation. Table 2 summarizes the findings of the Physical Environment of the Nursery component. The ratings for this component were the same for all five mothers and their babies.

Table 2. NIDCAP: Physical Environment of the Nursery

Dimension	Score
Location in relation to the Labor and Delivery Floor and Mother's Postpartum Room	2
Appearance	3
Physical Layout	3
Density and Size of Bedside Space	3
Design of Bedside Space	3
Conduciveness to Enhance Family Participation	2
Conduciveness to Enhance Professional Care Components	4

The NIDCAP Physical Environment of the Infant's Bed space subscale (see Table 3) focuses further on the environmental components that relate specifically to each infant. The components that are evaluated include: light, sound, and activity levels, visual stimuli within the infant's bed space, olfactory inputs, the infant's bedding materials and clothing, and self-regulatory supports. Just as in the NIDCAP Physical Environment of the Nursery, items are rated in Likert format. *Light level* is rated as (1) if the infant is cared for at all times in an environment of bright florescent overhead light; (5) refers to infant being cared for in appropriate levels of light for the infant's level of alertness (i.e., dark when sleeping, light when alert). All five infants experienced a high degree of light level without regard to individual needs.

In terms of *sound and activity levels*, both Patty and David and Lindsay and Bryce remained in the back room of the NICU, which houses 10 infant bed spaces. The sound and activity levels are somewhat decreased in this area, given the smaller space and limited number of beds. In terms of *visual stimuli* within each bed space, all of the infants experienced visual inputs that did not seem to pertain to their visual experience or state organization. The beds contained a flannel hospital blanket which was wrapped around the mattress. The infants' bed spaces were not decorated; there were no toys, blankets, and pictures of the infant's parents or items from home. The spaces were devoid of color and texture. The infant's experiences with *bedding and clothing* varied. During David's last week in the nursery, he wore a soft hat and a cozy one-piece romper, which his mother brought from home. He also received skin-to-skin holding most afternoons. In contrast, Chloe, Aiden, and Kiki, received less individualized bedding and clothing. They were also born much earlier and remained in the unit longer, and it

seemed that the younger infants did not wear clothing, just a diaper and a hat; they were

swaddled in hospital blankets and placed in a u-shaped nest. The clothing, bedding and

nesting materials were all routinely applied, without specificity to the individual infant's

needs. *Self-regulatory aids* refer to the use of possible aids (e.g., buntings, pacifiers,

being cradled by hands, sucking on mother's breast) to support the infant during

uncomfortable procedures, soothe infant for sleeping, or to help infant shift into a calm

state. Within this context, self-regulatory aids were used frequently, yet uniformly and

routinely. For instance, all parents were encouraged to provide skin-to-skin contact,

nurse infants, or hold infants.

Table 3. NIDCAP: Physical Environment of the Infants' Bed Space

Dimension	Patty & David	Cindy & Chloe	Grace & Aiden	Lindsay & Bryce	Kara & Kiki
Light Level	3	2	2	2	2
Sound Level	2	1	1	2	1
Activity Level	2	1	1	2	1
Visual Array Inside of Incubator Space	1	1	1	1	1
Olfactory Inputs	3	3	3	2	2
Bedding and Clothing	4	2	2	3	2
Specific Self-Regulatory Aids	3	3	3	3	3

Introduction to the Sample

Six mothers of preterm infants were enrolled in the study; one of the mothers did

not complete data collection, as she was not available for the last two interviews or the

caregiving observation. All of the participants' names have been changed in order to

protect their confidentiality. Table 4 provides basic demographic data for each of the

participants.

Table 4. Demographic Data

Mother	Mother's Age	Marital status	Race	Education	Occupation	Household members
Patty	27	Married	Caucasian	12 years +	Dental Assistant	Mother with biological father
Cindy	27	Single, Father involved	African American	12 years +	Janitor	Mother with baby
Grace	29	Living together *got married	African American	12 years +	Comcast call center	Mother with biological father
Lindsay	18	Single, Father not involved	Caucasian	9-12 years	Student	Mother, maternal grandmother and maternal sister
Kara	21	Single, Father and father's family involved	African American	12 years +	Student	Mother, maternal grandmother, and maternal great grandmother

Infants' Physical Health and Medical Status

In addition to demographic data, information regarding the infants' medical

stability was also collected. Table 5 provides a summary of each infant's medical status.

The following data points were collected via chart review for all five cases: birth

gestational age, birth weight, Apgar scores, respiratory care received in the NICU,

surgeries, and total days in the NICU. The infants' gestational age ranged from 22-32

weeks gestation. The birth weight ranged from 860 grams (1lb, 14.3oz) to 1880 grams

(4lbs, 2.3oz). Three infants were considered *extremely low birth weight* (< 1000 grams),

one infant was considered *very low birth weight* (< 1500 grams), and one infant was

considered *low birth weight* (< 5lbs, 8oz). Apgar scores indicate how well the baby

tolerated birth (taken at 1 minute). Scores at 5, 10, and 15 minutes provide information

about how well the baby is doing outside the womb. The following categories are

considered when determining an Apgar score: breathing effort, heart rate, muscle tone,

reflexes and skin color. Each category receives a score of 0, 1, or 2. The Apgar score

has a range of 1 to 10. The infants in this sample received scores that ranged from 3-9 at

1 minute after birth and scores that ranged from 6-10 at 10 minutes after birth.

Respiratory distress is common in preterm babies because their lungs are

immature. Respiratory care delivered during the NICU stay consisted of mechanical

ventilation, continuous positive airway pressure (CPAP), and oxygen (O2) via nasal

cannula. Different types of respiratory care are often utilized in order to support infants

with lung disease. The most invasive is mechanical ventilation followed by CPAP and

then oxygen. Mechanical ventilation is the process of using a respirator to deliver regular

breaths (oxygen and pressure) to the infants' lungs. In effect, the machine breathes for

the infant while his or her lungs recover. Ventilator treatment is cumbersome and often

intimidating for parents as the air is delivered to the baby's lungs via an endotracheal

tube that is inserted through the baby's nose or mouth. Once the infant is ready, the

infant may move to CPAP. This machine does not breathe for the infant, but helps keep

the lungs open between breaths. Short prongs are inserted into infant's nostrils and

oxygen is blown in at a constant pressure. As the infant's lung function continues to

improve, he or she may no longer require assistance to keep the lungs open. He may,

however, require extra oxygen to maintain sufficiently high oxygen levels in his

bloodstream. Within this sample Patty's son (David) required the least intensive

respiratory care. He required oxygen via nasal cannula for 17 days and Grace's son

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(Aiden) required the most intensive treatment; he remained on a ventilator for 59 days, and then made the transition to CPAP for 46 days, at the time of discharge Aiden continued to require oxygen via nasal cannula.

Various surgeries are often necessary to support the infant's survival outside of the womb. Three infants required a procedure called *PDA ligation.* A PDA refers to Patent Ductus Arteriosus, which is a heart problem commonly appearing in the first few weeks after birth. The ductus arteriosus is a short vessel that connects the pulmonary artery with the aorta in the fetus. Before birth, the blood is sent directly from the right ventricle of the heart to the aorta, thus bypassing the lungs. A PDA refers to a ductus arteriosus that has not closed after birth as it normally would; therefore, the blood that should go to the body gets recirculated through the infant's lungs. As a result, the infant's lungs have to manage a much larger volume of blood. Infants may have more trouble breathing, along with poor weight gain and fatigue. The *PDA ligation* refers to a procedure to close the PDA. Three of the infants in this study needed a PDA ligation.

Days in the NICU ranged from 28 to 122 days in this sample. Patty's son David was the most mature. He required the least amount of medical intervention. He experienced an uncomplicated medical course in the NICU and was discharged home after 28 days. Grace's son Aiden was the most immature infant, born at 22 weeks gestation, weighing 560 grams. He required the most intensive intervention and remained on ventilation the longest. He remained in the NICU for 122 days.

Table 5. Infants' Medical Status

Mother	Gestational Age	Birth weight	Apgar	Respiratory Care	Surgeries	Days in NICU
Patty (David)	32 weeks	1880 gm. (4 lbs., 2.3 oz.)	1 min = 6 5 min = 7 10min= 8	O2 17 days	0	28 days
Cindy (Chloe)	28 weeks	860 gm. (1 lb., 14.3 oz.)	1 min = 6 5 min = 8 10min= 9	Vent 0 days CPAP 11 days O2 23 days	0	67 days
Grace (Aiden)	22 weeks	560 gm. (1 lb., 3.8 oz.)	1 min = 3 5 min = 4 10min= 6 15min= 7	Vent 59 days CPAP 46 days O2 122 d/c home on O2	PDA ligation,	122 days
Lindsay (Bryce)	26 weeks	1140 gm. (2 lbs., 8.2 oz.)	1 min = 9 5min = 10 10min= 10	Vent 8 days CPAP 44 days O2 47 days	PDA ligation, BL hernia repair	99 days
Kara (Kiki)	25 weeks	730 gm. (1 lb., 9.8 oz.)	1 min = 7 5 min = 7 10min= 7	Vent 20 days CPAP 39 days O2 20 days	PDA ligation	89 days

Mothers' Social Support

During our second meeting, each mother completed a self-report questionnaire,

the Norbeck Social Support Questionnaire - NSSQ (Norbeck, Lindsey, & Carrieri, 1981),

using a Likert scale. Respondents rated each network member on two subscales of social

support: emotional support and tangible support (Norbeck, 1981, 1983). The Emotional

Support and Tangible Support scores were combined for the Total Function score. The

Total Network score was determined by adding the Number in Network plus questions 7

and 8, which pertain to the length of time one has known each person in their network

and how frequently one has contact with each person in the network. Table 6 provides a

summary of the results and a comparison of each participant's scores to normative values for the NSSQ based on the 1995 scoring manual instructions.

The number of people or relationships in each participant's network ranged from 4-17. The participant's mother was listed most frequently as the first person in their networks, while the baby's father was listed most frequently as the second person in their networks. Family comprised the largest percentage of each person's network. Relationships with network persons lasted for more than five years or more.

Three of the participants (Cindy, Grace, and Kara) earned scores that were within normal limits. Two participants earned scores that were outside the norm: Patty and Lindsay. Patty's scores were one standard deviation below the norm in several areas: number of persons in her network (she listed four), emotional support, total function, and total network. Based on those four sources, her Emotional Support score indicates that she did not experience as much respect, love, trust, and affirmation from these relationships as women in the normative group. Patty's score indicated that she perceived her network as capable of providing more Tangible Support such as borrowing money or obtaining help if she is sick. The Total Network score is also a standard deviation below the norm. This is not surprising, as the score is based on the number of relationships one has in one's network.

In contrast, Lindsay earned scores that were one standard deviation above the norm. She listed 17 people in her network. She felt that she received sufficient emotional and tangible support from her social support network. Interestingly, there has been some debate in the literature regarding the use of network size, as it can create extraneous variance and is a source of measurement error (Gigliotti, 2011). Specifically,

"more network members implies more support, support scores from the entire network most heavily reflect both support ratings and number of supporters listed" (p. 1). Although Lindsay's scores were exceptionally high, it is possible that the large number of people in her network skewed her scores in Emotional Support and Tangible Support. Another explanation for her unusually high scores may be that she is a teenager who is living at home with her family; therefore, she has many more people living in her immediate environment than the other participants.

Table 6. Norbeck Social Support Questionnaire

Mother	Relationship number (Number in network)	Emotional Support	Tangible Support	Total Functional Support	Total Network Score	Sources of social support
Patty	4*	54*	27	81	39*	Sister, friend, baby, mom
Cindy	9	113	64	177	84	Mom, boyfriend, dad, friends, sister, aunt
Grace	8	117	62	179	81	Mom, dad, sister, husband, minister, MIL, FIL, aunt
Lindsay	17+	231+	107+	338+	163+	Mom, sisters, friend, counselor, neighbors, aunt, cousins, teacher
Kara	6	71	37	108	61	Boyfriend, mom, friends, grandma, brother

*1SD below mean, + 1SD above the mean, ++ 2SD above mean

Mothers' Emotional Well-Being

The participants were given the Mini-MASQ (Clark & Watson, 1995) in order to assess their emotional well-being; all of the women completed this survey within the first three to four weeks of NICU admission. Based on the Mini-MASQ scores (see Table 7 below), three of the participants (Cindy, Grace and Kara) earned scores that fell within

normal limits. Patty and Lindsay's scores were elevated when compared to the

standardized normative group. Patty scored 23 in General Distress, which is higher by

one standard deviation when compared to the norm. She scored a 22 in Anxious Arousal,

which is elevated by two standard deviations when compared to the norm. Patty also

scored a 25 in Anhedonic Depression, which is one standard deviation higher than when

the normative group. Lindsay scored a 24 in General Distress and a 28 in Anhedonic

Depression; both scores are elevated by one standard deviation when compared to the

norm.

Table 7. Mood Analysis: Mini-MASQ

Mother	General Distress	Anxious Arousal	Anhedonic Depression	Total Score
Patty	23+	22++	25+	70
Cindy	13	10	19	42
Grace	10	12	19	41
Lindsay	24+	15	28+	67
Kara	10	10	18	38

* 1SD below mean, + 1SD above the mean, ++ 2SD above mean

Mothers' Internal Working Model of the Infant

The Working Model of the Child Interview - WMCI (Zeanah et al., 1994) was

administered to the participants in order to explore their perception of their infant as an

individual and their perception of their relationship with their child. After completion of

the interviews, the transcripts were coded by WMCI co-author, Anna Smyke, Ph.D. Two

questions on the WMCI are germane to the categorization of the internal working model.

The questions relate to the mothers' relationship with her baby and the mothers'

description of her infant. These questions will be discussed below. A case-by-case

description of each participant's WMCI classification will follow. Table 10 provides a

summary of each of the WMCI categories and specific features of each woman's IWM.

Mothers' relationship with their baby. The participants' descriptions of their

relationships with their infant varied. Some mothers recognized the relationship as

evolving through comments such as "I don't know if we have one yet" and "budding",

others focused on how the relationship feels (i.e., exciting, worrisome), and how each

participant feels about her baby (i.e., "I really love her", "dedicated to being there to help

him"). Only a few participants were able to provide specific memories to support their

descriptions.

Table 8. Mothers' Descriptions of Their Relationship With Their Babies

Mother	Relationship Descriptors
Patty	• Exciting • Worry • "I don't know if we have one yet"
Cindy	• Budding • Exciting
Grace	• "Good bond" • "Dedicated to being there to help him"
Lindsay	• "I don't know"
Kara	• "Positive relationship" • "I really love her" • "It's really close"

How mothers described their baby. Table 9 provides a summary of descriptors.

One interesting finding is that three of five women identified their babies as "feisty" after

the nurses reported that the baby was feisty. It would be interesting to consider the role

that nurses' perceptions of the infant play in the mothers' internal representation of who

their baby is. All of the participants used positive attributes to describe their infant; even

adjectives such as "stubborn" and "feisty" were used to describe their infants' strength

and ability to get through this challenging time.

Table 9. Mothers' Descriptions of Their Babies

Mother	Baby Descriptors
Patty	Mellow Smart
Cindy	Feisty Calm Alert Girly Knows what she likes
Grace	Feisty Smart Determined
Lindsay	Active Stubborn Quiet
Kara	Feisty Sweet Strong

WMCI categories. Based on previous studies that explored the relationship

between internal working models and caregiving behavior in full-term infants and their

mothers, it appears that non-balanced WMCI scores were connected to a less sensitive

and more passive maternal interaction style (Sokolowski, 2007). Further, it seems that

non-balanced attachment representations were associated with behavioral differences in

both mothers and their infants (Rosenblum, 2002). For example, after experiencing a

disruption or a mismatch in the relationship, both members of the dyad demonstrated

fewer bids for reparation.

In this study, two participants (Patty and Kara) were categorized as *distorted* on

the WMCI. Throughout the interview, both mothers had difficulty focusing on the infant

and their relationship with their infant. For instance, the mothers' narratives lacked

coherence and contained inconsistencies when describing the child. The other two participants (Cindy and Grace) received a categorization of *balanced.* In contrast to a *distorted* categorization their *balanced* narratives were rich in detail and were characterized by integration of both positive and negative aspects of the relationship. Both Grace and Cindy were able to acknowledge frustrations with their role as parent as well as difficult aspects of their infants while also acknowledging their infants as individuals. The following is a description of the internal working models of four of the participants who participated in the WMCI: Patty, Kara, Grace and Cindy.

Patty demonstrated a distorted internal working model of her relationship with David. Much of her narrative consisted of her recollection of a traumatic delivery, followed by prolonged separation from the baby, and her sense of isolation. Very little of the interview focused on David specifically, even when confronted with questions that required her to talk about him. For example, when Patty was asked, "what do you think is special about your baby?" she responded, "I'm pretty sure we're gonna baby the hell out of him because he's a special little kid. And he's the first one in the family so he's gonna be spoiled rotten." Her responses did not convey a knowledge of David as a person. In fact, she was uncertain if they actually had a relationship:

> He's dependent on everybody else. He's got a relationship with the whole surroundings right now. I'm hoping he's aware of me. I don't know if he is.

Patty also demonstrated the lowest scores on the Mini-MASQ; she scored two standard deviations below the norm in depression, anxiety, and distress. Additionally, Patty had limited social support. Her scores on the NSSQ were below average, particularly for the number of individuals who can provide support, specifically

emotional support. In fact, when asked to list the names of people in her social support network on the NSSQ, Patty listed her infant David. The names of people listed on the NSSQ, typically contain names of individuals who are capable of providing physical, financial and social support. Clearly, writing David's name down was unusual, and possibly consistent with a role-reversed distorted representation of the relationship, in which the infant is expected to care for the parent.

Patty's case supports the influence of emotional well-being (Korja, 2009), a distorted internal working model of the relationship (Borghini et al., 2006; Korja, 2009; Korja et al., 2010; Meijssen et al., 2011), and limited social support (Davis et al., 2003; Easterbrooks, 1988; Lau & Morse, 2001) for the mother's experience of prematurity. Her case further highlights the importance of labor and delivery as well as the first moments caring for the baby as the early foundation for the relationship.

Kara also exhibited a *distorted* internal working model of her relationship with her daughter Kiki. Kara's responses were inconsistent and often difficult to comprehend. For instance, when asked how she thinks Kiki will respond to separations in the future, Kara responded:

> I feel like since she's been up here, the nurses, they're there but like the – always contact, babies being held, all that when they're first born and all, I think she's kind of used to not that, so I feel like she'll definitely adapt better to me not being around if she gets dropped off, or you know, I'm not – she's gonna be clingy and spoiled, but then again she still might be spoiled, so. (Interview 2, p. 4)

Kara also had difficulty focusing on Kiki during the interview. For instance, when asked about any difficult times she may anticipate in Kiki's development, Kara responded:

> I don't really like girls, not at first. But I feel it's gonna be hard just dealing with a girl, period. Because I'm a girl, and I don't really mesh well with a lot. (Interview 2, p. 12)

Kara made insensitive statements about Kiki's appearance. For instance, when asked if

she had any concerns about Kiki's future development, Kara stated:

> I think her ear is so ugly because she always lays on it, so it's like bent up. I feel like that ear is gonna get ugly. Yeah. That's a setback for a girl. They can't be having ugly ears. What else? She's gonna get bed hair from all this laying down. So hopefully it grows right. (Interview 2)

Lastly, she described her relationship with Kiki, a critically ill newborn in the NICU as

"fun." When I asked if she could recall a specific memory to support this description, she

stated:

> Yeah, she tries to laugh sometimes. And I just laugh with her a little bit. I just talk to her. And she knows my voice, and I feel like she understands me and everything… because one time she – like she doesn't want to open her eyes, or she just wants to open for her father, and I was just like, um, I'm like: your dad's here. And she wants to open her eyes. And I'm like: oh, now you want to open them. And then she tries to like laugh, and I'm like: right. You only try to open them a lot when he's here. And she just tried to laugh, and I just laughed with her a little bit. She's fun. (Interview 2, pp. 16-17)

Cindy, in contrast, exhibited *balanced* internal representations of her relationship

with Chloe. Her responses were characterized by an acknowledgement of both positive

and challenging aspects of the relationship. The following contains Cindy's response to

how she imagines her first week home with Chloe.

> Well, I hope it's just – she doesn't cry that much here, so she won't cry that much at home. I don't imagine that it'll be too bad. I think it'll definitely take some getting used to, because it's going to be my first time, but I don't imagine it'll be too difficult, I hope. Plus, I won't have to do any work, so I think I'm looking forward to it. If we can just sit down and do nothing together. (Interview 2, p. 3)

She described her relationship with Chloe as

> I think we're both, like, trying to figure each other out. So I guess it's just, like, really new. It's a relationship – with all the good stuff. Also looking for all the things that – well, I guess not necessarily bad, but difficult, I guess, as far as raising a child…the honeymoon stage. Parent-child relationship, and then as she gets older, I'll be like, things that she can do, it's, like, more difficult. I'll be like,

> oh, okay, I see the ups and downs of parenthood. So it's all on the upside right now. She can do no wrong. She's a baby, so. (Interview 2)

Cindy's descriptions of her future with Chloe reflect an openness to change, meaning there is room in her representation of Chloe to continue to accommodate change that will occur. The following is Cindy's description of how she anticipates feedings will go once Chloe is home.

> Well, that's funny. I guess I'm just worried because I – she's so little, that I'm like – I'm interested to see how it's gonna go because I feel like, I don't know, it might be – it'll be interesting. I guess that's the best word to put it. So I guess if all else fails, she can still drink from the bottle. But I don't know, I guess I would anticipate it going smoothly if she's drinking from the bottle in – I don't know. (Interview 2, p. 4)

Finally, Cindy not only acknowledged Chloe's individuality, but she responded to her preferences empathically. In the following quote, Cindy was providing an example for her description of Chloe as someone who "knows what she likes".

> I thought of something else for the "knows what she likes". One day, I wore a – because you know you can kangaroo, and I wore a shirt that I guess was too tight for her, because she did not like it. Like, she was making noises the entire time. The shirt must have been on her back, that's why she didn't like it. But since then, I've never worn another shirt that was too tight, and she's been okay. (Interview 2, p. 13)

Grace also demonstrated a balanced internal working model. Grace's son Aiden was the sickest of all of the infants, he was in the NICU the longest and he experienced a series of setbacks and victories. Grace was by his side through all of these experiences. Although she was unable to hold him for almost a month, she remained present to support Aiden in whatever way she could. She watched Aiden carefully in the incubator and offered her hand to comfort him when he was uncomfortable. She developed a strong

understanding of Aiden's needs and eventually began to advocate for more pain medicine when he seemed particularly uncomfortable.

When the WMCI was conducted Aiden was still quite ill and the doctors were cautious about his prognosis to survive as he was born at only 22 weeks gestation and had significantly underdeveloped lungs. During the WMCI interview, Grace was uncomfortable when asked about Aiden's future. She was unsure of how to answer questions related to her relationship with Aiden because at that point he was unable to open his eyes, generate an audible cry, or even remain alert for more than a few moments. Grace reported that she and Aiden have a good bond. She stated, "I know I just wanna be there for everything that he goes through…because I love every moment I get to see him" (Interview 2). When asked about what will please her most about Aiden as he grows up, she stated, "It's just knowing…that he's happy, if he's not in any pain or sick, you know. Just being a normal child."

Table 10. WMCI Categories

Mother	WMCI category	IWM special features
Patty	Distorted	Confused
Cindy	Balanced	Restricted
Grace	Balanced	Full
Lindsay	No data	No data
Kara	Distorted	Confused

Individual Case Presentations

This section begins with a description of the caregiving observations and the

phenomenological interviews followed by the presentation of each of the five cases. In

order to contextualize each case within the lives of the participants, each case analysis

will start with a review of each woman's background and pregnancy. Next, themes from

the interviews will be discussed, followed by a review of the caregiving observation. The

section will conclude with a compilation of the relevant themes for each case in the form

of a table (see Table 12).

Caregiving Observations

All of the subjects participated in mother-infant caregiving observations. These

observations consisted of either mothers changing their infants' diaper or feeding their

infant. The purpose of the observation was to learn about the infant as an individual, the

mother as a caregiver, and how the dyad engages with one another. The observation was

a neurobehavioral NIDCAP observation (see Appendix F) based on the synactive theory

framework. Within this framework, the infant was considered in terms of his unique

capabilities for maintaining physiological stability at rest and during caregiving. As the

infant was observed with his mother, his availability for social interaction as well the

robustness of his stress communication was noted. Finally, the mother's ability to notice

and respond to the infant's stress during caregiving was considered.

When conducting qualitative work, the researcher is considered an instrument, as

all of the information that is obtained is filtered through him or her. Therefore, I feel it is

important to disclose (as I mentioned in Chapter III) my own professional background. I

have worked with premature babies in the NICU and after discharge in the capacity of a

developmental specialist and a speech-language pathologist. As a developmental specialist, I obtained extensive training in neurobehavioral observation over a period of 18 months, leading to a NIDCAP certification. Additionally, I am a licensed pediatric speech pathologist and feeding specialist with extensive training and clinical experience working with infants that have been afflicted with dysphagia (difficulties feeding and swallowing).

My expertise, therefore, has allowed me to view these caregiving observations with a careful eye for infant behavioral communication as well as the infant's specific motoric and sensory abilities needed for feeding. For example, necessary oral motor capabilities include lip rounding and tongue cupping to provide suction in order to extract fluid from the nipple, jaw excursion to support lip rounding and tongue motion, maintaining a tucked and midline body position in order to support stable oral motor movements. Oral transit of the fluid from the front of the mouth to the back of the mouth is supported by tongue cupping in order to form a bolus with the liquid and transport it to the back of the mouth in order to initiate the swallow reflex. Additionally, observing the infant's ability to coordinate sucking, swallowing, and breathing throughout the feeding. Infants in the NICU may have underlying challenges that compromise this coordination, such as cardiac conditions which impact endurance to perform such a physically demanding task. Neuro-motor challenges may impact tongue range of motion and strength or sensory awareness, thus affecting the infant's ability to prevent the liquid from slipping into his trachea (airway) rather than his esophagus. When food or liquid slip into the trachea, a cough response is typically generated, however, this reflex may not be triggered in neurologically complicated infants or it may be ineffective if there is a

very large bolus, thus resulting in aspiration (food/liquid entering the lungs). Repeated

episodes of aspiration may lead to pneumonia. Therefore, feeding assessments are

routinely performed by speech pathologists or occupational therapists within the NICU

and after discharge.

Initially, I had planned to complete feeding observations of each dyad, as feeding

is such a central part of the mother-infant relationship and is such a physically complex

activity for premature infants in particular. I felt that there were many aspects of the

infant's communication to attend to and many opportunities for the participants to

support their infants. Unfortunately, it was not possible to obtain feeding observations

for every participant, given that feedings needed to be scheduled according to the infant's

schedule as well as to comply with the schedule the medical team determined as most

appropriate on that given day and in that given moment. Therefore, the caregiving

observation was modified to include all caregiving activities. Three mother-infant dyads

were observed during a feeding, two dyads were observed during a diaper change, and

one dyad was observed with both feeding and diapering. Table 11 provides a summary

of which participants were observed feeding and/or diapering their infants.

Table 11. Type of Caregiving Observed

Mother	Diaper Change	Feeding
Patty	x	x
Cindy		x
Grace	x	
Lindsay	x	
Kara		x

Phenomenological Interviews

Four out of five subjects participated in the three-part, phenomenological interview. One subject (Lindsay) dropped out of the study before her final interview. The focus of the first interview was on the pregnancy, labor, and delivery. The second interview consisted of the WMCI, which consisted of questions regarding how each mother perceives her baby, her relationship with her baby, and how she imagines the baby will be as he/she matures. The final interview took place during the week of discharge. Although this interview was open-ended, it tended to focus on the mothers' concerns regarding bringing the infant home, supporting the infant in learning to eat by mouth, and reflecting on the NICU experience as a whole.

Case #1: Patty and David

Background. Patty is a 27-year old married woman who became pregnant unexpectedly. She resides in an apartment with her husband near O'Hare airport, approximately 30-60 minutes from Midwest medical center, depending on traffic. Prior to giving birth Patty was working and going to school. She left her job and took a leave from school so that she could be present for David in the NICU.

Her mother and sister live in the Chicago area. However, she does not see either very often. She dismissed her limited contact with her family, "everyone is really busy; they can't sit with me all day." Nevertheless, themes of loneliness and lack of support emerged throughout her case. For instance, she was alone when she was brought to the hospital, during hospitalization, and on the delivery table after David's birth.

Based on the descriptive data presented in the previous section, Patty exhibited scores that fell one standard deviation below the norm in the areas of social support

(particularly emotional support). Her scores on the mini-MASQ indicated elevated scores in the area of depression and anxiety. Her WMCI score revealed that she had a distorted internal representation of her newborn son David.

In comparison to the other infants in the study, David was the most mature, required the least amount of physiological support in the NICU, and the physical location of his bed in the NICU was the most ideal location. David's bed was located in the back room, a smaller NICU space that contained only 10 infants (the large room contains approximately 40 infants when at capacity). Within this room, David's bed was located in the far corner. He was positioned farthest from the nursing station, therefore, he was subjected to the least amount of noise from phones ringing and nurses talking. Additionally, the privacy curtain was able to fit around David's bed space and attach to the wall so that Patty had complete privacy when she came to hold David via skin-to-skin care or nursing. The following is a description of key themes that emerged during three interviews and two observations of Patty caring for David in the NICU.

Pregnancy. She described the pregnancy as surprisingly easy. In fact, Patty didn't feel pregnant at all, because she felt so well. The pregnancy became real to Patty when she completed routine lab work at 20 weeks gestation, which revealed the baby's increased risk for spina bifida. After continued testing via maternal-fetal medicine, Patty's was relieved to learn that her baby had a very small chance of developing this condition.

Patty delivered David via unplanned premature labor when he was 32 weeks old. David was the healthiest and most mature baby in our sample. Patty often reported that she felt guilty because he was so much larger than the other infants in the NICU and he

appeared to be progressing more quickly to breathing on his own and eating by mouth.

She felt guilty not only for David's size and progress, but also for her own feelings of

grief. She visited David daily, arriving with David's father most weekends and alone

most weekday afternoons. She eagerly accepted feedback from the nurses regarding

caregiving strategies for diaper changing, bathing, and feeding.

Themes from interviews with Patty. *Unexpected labor and delivery.* At 31

weeks gestation Patty arrived for a routine prenatal visit only to learn that her amniotic

sac was leaking fluid. She was transported from her doctor's office to the hospital via

ambulance. Patty was hospitalized and placed on strict bed rest for one week until she

went into active labor on her own. Patty felt unprepared for labor, as she had not yet

taken her childbirth classes. She describes her delivery of David as a difficult time when

she was physically unwell and also trying to cope with the pain from the C-section

incision:

> I don't remember seeing him much when we were in the OR I started throwing up
> because of the anesthesia" (interview 1, p. 19). They took me to a recovery
> room. Because I was throwing up, they didn't let me go see him. I was
> essentially throwing up the whole night. With the stitches, it was pretty painful.
> (p. 20)

> *Few opportunities to be with David during the first few days after birth.* Patty

described a difficult night waiting to meet David for the first time the next morning:

> They would not let me see him…this area is closed from 9:30 am to 12 pm. I was
> waiting for my nurse to come in, but the shift was switching. She came in 15
> minutes before closing time in the NICU…She wouldn't let me go until I ate
> something. They did bring me here somehow, 10 minutes before 9:30 am, so I
> got to see David for 10 minutes. That was pretty hard…I think I was just so
> exhausted I didn't know what to think. (Interview 1, p. 21)

Patty was upset because of the long stretch of time that elapsed between giving birth to David and finally getting to see him. "I was really mad I didn't get to see him earlier too. I was waiting for my nurse to come in since 6:00 in the morning" (p. 22). After Patty met her baby for the first time, she was physically exhausted, overwhelmed, and disappointed. Patty recalled how she felt the first time she entered the NICU:

> It was hard. He's not the smallest baby here, and he's doing very well. Still, it was hard to see. There's tiny little oxygen, and everything else, all the tubes and wires, and everything coming out his nose.

Furthermore, Patty did not have many opportunities to be with David prior to being discharged from the hospital. Patty recalled cuddling with David on the day she was discharged, which was just three days after David's birth.

> I came to say goodbye and I just started bawling. Then the nurse decided to stuff him in my shirt for a little bit. I snuggled his head, I was crying. (He felt) very, very fragile, little…he was really red and jittery; it was scary to touch him. (Interview 1, p. 25)

As she further reflected about her labor and delivery, Patty stated, "I feel a little cheated, I wasn't ready to have him outside of me."

Nurses as providers of social support. Since Patty did not have many people in her social support network to draw on during and after her premature delivery of David, the support she received from the nurses in the maternity ward was particularly influential:

> I was stuck in the ICU for a week; they would just come in to each lunch with me or breakfast with me because I was there alone a lot of times. So these are the nurses that actually made me survive there. They wouldn't allow me to leave the bed for anything. I had to pee and everything laying down. And that was terrible, and I couldn't get up to shower. And I was stuck in bed for that time. The nurses were wonderful people and they would come in and offer to brush my hair and just hang out with me for a little bit and definitely make a huge difference. I probably would have lost my mind if it wasn't for them. (Patty, Interview 3)

For Patty the social support received from nursing seemed to act as a secure base for her

to be able to take on her role as a new mother to David.

> They're wonderful people. They're teaching me everything, showing me what to
> do, everything, making it more comfortable [inaudible] which is kinda necessary,
> since he's going home soon. At least one nurse that sat with me and told me all
> the little ins and outs of the tricks that she's known and she's used since she was a
> mom, and now she's a grandma. So she told me all those little things – if this
> happens you can do this and this happens and you can do this. And if I needed
> help with burping him she'd help me and tell me which position to put him in.
> (Patty, Interview 3)

> ***Baby in a glass box.*** During her final week in the NICU, I asked Patty if she

could put this experience into words. Patty grew emotional as she recalled the

helplessness and disconnection she felt from David in her early days in the NICU.

> You kind of have to watch him in a glass box, and see everybody else take care of
> him because they know better. Here I am sitting clueless, kind of observing and
> not knowing anything. I don't get to take him home and he's not really anybody.
> It feels like he's not a little person…a number more than anything in the
> beginning. You have everybody running around and trying to make sure that
> everything's okay…You can't talk to him and he is just kind of laying there, can't
> touch him too much because his little system's not developed yet, so we're not
> supposed to mess around with it too much. It's a little glass bowl. My last
> name's on there, so I guess he's mine, right? (Interview 3, p. 9)

After one month of David's hospitalization, Patty was asked to describe David,

> I wish I had a lot of words to pick from, like a dictionary or something (Interview
> 2 p. 53). That's the hardest question, it should be the easiest question, but it's not
> easy…I don't know his personality yet. He's always asleep, that's one thing I can
> tell you for sure, he barely ever wakes up…He's gonna be awake more when he's
> hungry more, so I'll get to know him a little bit better. (Interview 2, pp. 54-55)

Patty eventually described David as "very mellow" and "smart". Patty thought David

was mellow because he was often quiet or sleeping while the other babies next to him in

the NICU were often fussing. She reported that it is difficult to get to know David when

all of his basic needs are already cared for in the NICU:

I need to spend some one-on-one time with him. I need to get to know him when he's hungry and when he's angry and everything else. I come here and he's always content, he barely cries. (Interview 2, p. 8)

In fact, Patty was not sure if she even has a relationship with David yet. "He's got a relationship with the whole surroundings here right now. I'm hoping he's aware of me, but I don't know" (Interview 2, p. 25).

Caregiving tasks build the relationship. Having opportunities to engage in caregiving tasks provided Patty with an opportunity to get to know David. She commented on the difference nurses made in assisting her in learning to care for David. Just two weeks after David's birth, Patty reported, "they finally let me hold him. The nurse is actually encouraging me to change diapers now" (Interview 1, p. 26). Patty seemed especially pleased that she can now take David out of the incubator on her own when she comes to visit as she feels she is a lot more confident and comfortable with him (p. 27).

Patty recalls her first memory of changing David's diaper as one of the most exciting experiences in the NICU,

Well, the first time I got to change his diaper was super exciting. He peed everywhere but that was even more exciting to get to see my baby and what's gonna happen. And I actually got first time hands-on something or another. I got to actually do something and I felt like it was my baby. (Interview 2, p. 29)

Caregiving observation of Patty and David. Patty visited David daily in order to hold him and participate in caregiving; her consistent visits helped her get to know David's preferences. Furthermore, Patty was responsive and proactive in obtaining education from the nurses regarding caring for David. Patty was a cautious caregiver. She paced herself throughout caregiving tasks. However, she did not consistently see

David's behavior as communicating his needs. As a result, she became intrusive in terms of exerting her desires on his behavior. For example, when David arched his back during feeding, she physically moved his body back to flexion, rather than interpreting the arching as purposeful. Furthermore, she also misinterpreted or distorted his behavior. For instance when asked about David, she reported, "I feel like he smiles at me usually. He doesn't smile at anybody else. Then again, I tease him, and tickle him, and bug him all the time" (Interview 1, p. 17).

David was capable of maintaining physiological stability such as a steady respiratory rate and heart rate during caregiving activities. He was able to soothe himself by sucking on his hand and maintaining a tucked posture and bringing his hands to midline. When observed during feeding, David had difficulty latching onto his mother's breast. Based on this observation, it seemed that David had trouble obtaining enough proprioceptive input in order to cup the breast with his tongue and thus initiate a productive, nutritive sucking pattern. As a result, he was unable to trigger a let down response. Without receiving milk, David quickly lost interest and fell asleep. Patty grew increasingly frustrated, attempting to reawaken David and push her breast into his mouth. David did not move into an alert state, she continued trying to bring him into an alert state, but he remained asleep.

When observed during diaper change, the dyad appeared to connect more consistently. Patty told David she was going to change his diaper, and gently laid him down in his bassinette. She slowly unwrapped his blankets and spoke to him softly. David watched his mother, making eye contact with her as she removed his layers of clothes. She rolled David to his side in order to wipe his bottom while verbally noting

that he did not like the moist wipe on his bottom. She spoke to him gently as she carefully reapplied a clean diaper. David participated in the diaper change through his alert state and eye contact. His heart rate and respiratory rate remained stable throughout the diaper change.

Case #2: Cindy and Chloe

Background. Cindy is a 27-year-old unmarried woman who is in a relationship with the baby's father. Cindy's extended family (i.e., parents and siblings) live in Colorado. She reports that the distance does not affect the level of support she feels from her family because they speak often by phone (CG, Interview 3, p. 1). Cindy is saving her maternity leave for after the baby gets discharged home. She works during the day and comes to the NICU at night. Based on the descriptive data presented in the previous section, Cindy exhibited unremarkable scores in the areas of emotional well-being and social support. Her score on the WMCI revealed that she had a balanced internal representation of her newborn Chloe.

Pregnancy. Cindy's pregnancy was unexpected; however Cindy felt excited about the pregnancy and looked forward to meeting the baby. She described her pregnancy as pretty smooth, "the entire time I didn't have any like morning sickness or anything up until right before I had her" (Interview 1, p. 1). The pregnancy began to feel real to Cindy after she had her first ultrasound at 13 weeks and heard the baby's heart beating. The pregnancy was uneventful until Cindy developed a rash on her feet and her blood pressure was unusually high.

Themes from interviews with Cindy. Cindy's interviews reveal one major overarching theme, *coping with the unexpected*, and a number of subthemes that highlight her struggle during this time.

Pregnancy complications become life threatening. Cindy went to her obstetrician to discuss her rash and blood pressure. The doctor was very concerned about her blood pressure. As a result, she was admitted directly to the intensive care unit, where she remained for ten days until she was ready to deliver Chloe. Cindy reported that she did not really understand what was happening as this was her first time in a hospital. Cindy had developed a condition called *preeclampsia* which can prevent the placenta from receiving enough blood thereby limiting the infant's growth in utero. She was eventually told that she would need to remain in the hospital for two months so that Chloe could reach a gestational age of 34 weeks. Cindy tried to make peace with her new circumstance, "I was not excited about it, but I guess it's what's best for obviously her and so then what's best for me, so I have to do whatever I have to do" (Interview 1, p. 10).

Unfortunately, as the week progressed it became more apparent that Cindy would need to be induced. Cindy's blood pressure continued to be elevated, and she was not responding to antihypertensive drugs. Her doctors became concerned about Cindy's risk for a stroke. Furthermore, her doctors were also concerned about the dramatically reduced blood flow to the placenta. The medical team felt that Chloe's brain and organs could be compromised. Cindy reported the decisions that led to induction of her labor and subsequent delivery of Chloe.

On that Friday, at 5:30 in the morning they had said that her heart rate had dropped for three minutes, and they had always told me before if it drops to five minutes then they are going to deliver her, so she dropped for three minutes and they came back. So they were telling me well, it was kind of like a half of the requirement, so then they said well, if she drops again we want to do it. I was like I guess. I mean she came out really early, so it wasn't something I really wanted to do, but if that was what's best for her then, you know and I didn't have much choice. (Interview 1, p. 8)

Too sick to be really present to meet baby. Chloe was eventually delivered via C-section. Cindy recalled the first time she saw her baby:

I was lying there and then they had her to the right. I guess they were cleaning her off, so I couldn't see her – it felt like a while, but I don't know because I couldn't see a clock. But then they finally – they just like brought her over next to me right before they I guess took her to the NICU in like a very short time. I didn't see much, and then plus I was all drugged up, so it was very, very brief. …It was so quick I can't even remember what I thought…I guess I'd say overwhelming. I was surprised she was so little. (Interview 1, pp. 11-12)

This experience was very disheartening and confusing for Cindy, "you expect to hold your baby and all that, but it wasn't, like I missed that" (Interview 1, p. 11).

"Was I really pregnant?" For Cindy, events unfolded quickly and unexpectedly. Cindy reported:

I didn't deliver her the way most people do, that's what you expect to happen...I didn't even feel pregnant, then she came early, and my body was back to its regular size, clearly I was pregnant, she's here. It happened so fast, and like I had almost the opposite of everybody's pregnancy experience. (Interview 1, p. 11)

Cindy's experience further underscores the delicate transition from pregnancy to becoming a mother. In his book, *The Birth of a Mother,* Daniel Stern (1998) highlights pregnancy and giving birth as a time of preparation to being a mother. Stern emphasizes the importance of imagination for a new mother, how she works and reworks her future in the landscape of her mind in order to adapt to the dramatic changes in her life. For Cindy, having a preterm baby felt as though she was stuck somewhere in between three

different worlds: pregnancy, motherhood, and life before pregnancy. The short duration

of Cindy's pregnancy, the prolonged separation from Chloe, coupled with her weight

loss, created a very uncomfortable and confusing space in time.

Cindy recalled how after the delivery Chloe was rushed to intensive care while

Cindy was told by her doctors to remain in bed for approximately 24 hours. "It was kind

of sad because it was like the first time you're supposed to be her mom and this is your

baby and I'm stuck in bed, I can't go anywhere. So it was upsetting" (Interview 1, p. 15).

During that time she wondered if she was ever pregnant. Cindy coped by trying to sleep

for most of the day, and waiting to receive pictures of Chloe from the baby's father (who

was able to be in the NICU with Chloe).

Trying to stay positive when things don't go according to plan. The next day

Cindy was able to come to the NICU to meet her baby girl. She remembers feeling

excited to see her, but then felt discouraged because Chloe was lying in an incubator.

She continued to notice how this early journey into parenthood was not going as

expected. She reported that it was "good so I can see her, I can touch her, but I still can't

hold her" (p. 16). Cindy tried to focus on the positive:

> All she does is sleep…she moves around in her sleep, so I guess that was
> comforting. And it was good because the nurse was there, and she seemed really
> knowledgeable, so I asked a lot of questions. I don't know, it's like my baby is
> stuck. It's good, but then it's tough. It's frustrating, every day is hard, when is
> she gonna get out. And I know she said it's gonna be a while. Things like
> gaining weight are good things, (it means) she's getting closer to coming out then.
> (p. 18)

The cumulative effect of an unexpected pregnancy, labor, and delivery was

wearing on Cindy. "I figured if I delivered early, it would be like 34 weeks, not this. I

figured that maybe she would come in September, so she'd still be big enough to take

home" (p. 18). Cindy tried to be patient and remind herself that even though Chloe is in the incubator, she is thriving (p. 17). However, she longed to be with her daughter, "yes, it's good she's being taken care of, and this is the best spot for her at the moment, but I rather she be at home" (p. 17). A week later, Cindy was finally able to hold Chloe for the first time. Cindy reported,

> It was really good; it made me cry. But it was like crying with relief. Just like finally being able to hold her, because that's what you expect to do. I felt like I can better take care of her then the nurses. It felt like she was more protected, more taken care of because she was with me, rather than in the box. (p. 21)

As the time approached to discharge Chloe, Cindy grew particularly agitated because the discharge date was pushed back several times as Chloe began to demonstrate an irregular heart beat during feedings. The medical team determined it would be best to observe Chloe for another week. Cindy was devastated: "I feel stuck, and I just want to rip out of here. I don't care what you guys have to say. I'm feeling kind of like I'm the mom but I have no control. I'm beyond frustrated, it's been a long two months" (Interview 3).

   Pumping breast milk as caregiving. Cindy felt that pumping breast milk was one of the few things she could do for her daughter while she was in the NICU, and she wanted to do this job well. She wanted to produce enough milk so that Chloe would not need to receive any formula as supplements (p. 26).

   Although she intended to breastfeed, Cindy was surprised how often feedings occurred. Cindy's desire to perform this caregiving task well quickly led to anxiety about her ability to keep up with the demands of pumping breastmilk (p. 25).

> It's just frustrating because I feel like she's increasing her feeding, which is good. She's eating more and more, and I don't think I'm behind (with pumping breast milk), but…it takes time for my production to really get going…I guess my body is producing, but not how I want it. (pp. 25-26)

Breast pumping became yet another symbol of the way things were not going as

expected.

> I guess I think feeding is different than pumping, using a machine to get out breast milk, versus having her. I think it would be better because right now, it's almost like an annoyance, and maybe it won't feel like an annoyance anymore because she is there…It's like, 'oh, it's time to pump again' I just dread it. I feel bad, but you know, you have to do it, so you do it anyway. (Interview 2, p. 1)

> ***Need for privacy and more time together.*** When asked if there were any barriers

that obstructed her relationship with Chloe in the NICU, Cindy wondered what it would

be like to be in a NICU without distractions.

> Because she's in a hospital, her nurse is with her the majority of the time versus me and her dad or family members. There's a lot of distraction here. It's distracting for her too. If it could just be quiet, she's used to all this noise. Like babies who are in their mom's stomachs, they don't hear all this, on high alert type of noise… It's just distracting; it makes you always on edge.

Cindy reported that sometimes she watches the monitors more often than her baby.

> ***Impact of NICU on Cindy and Chloe.*** Cindy discussed how she thinks this

experience of giving birth to a preterm baby who has been hospitalized in the NICU has

affected her.

> I think because we're just way more overprotective in general now. People are protective of babies, but now it's like, I barely want anyone to touch her. It's like me or her dad. I don't know, I'm extra paranoid. So I think that will definitely impact – until she gets a little bit bigger, and then I think I'll be okay. Because even they were saying if she gets sick, then she's going to get admitted. And it's like, "Aarrggh!"…We already didn't want her to go to daycare, and now it's like, "Oh, she's definitely not going to daycare. Those kids would get her sick. So I don't know, I think – like I said, it just makes me more overly cautious, and maybe slightly paranoid. (CG, Interview 3)

She also considered the impact of this experience on Chloe:

> Hm. I guess her experience is so different, but she's not gonna remember that, so. I think she'll probably have, like, a leader personality. So maybe she'll stand out.

Because I just have – I feel like she's gonna be, like, what's a good word? Strong. I just think she's gonna be, like, outgoing, but outspoken too, and, like – hm. I don't know. (Interview 2)

Caregiving observation of Cindy and Chloe. Cindy visits Chloe daily. She was observed with Chloe on two occasions, first in September, approximately six weeks after admission into the NICU, and second at discharge. During the first observation, Cindy seemed anxious; she spoke quickly. Her affect seemed overly bright at times, even when discussing sad or unpleasant experiences. She reported that she does not see Chloe as being fully developed, because she is still supposed to be growing in her womb.

During the first observation, Cindy was holding Chloe in her arms as she received her feeding via a nasogastric tube. Chloe lay in a drowsy state as the last few drops of breast milk trickled from the syringe; she maintained eye contact with her mother. Cindy smiled at Chloe and spoke to me excitedly about Chloe's progress. During this observation Cindy was able to recognize Chloe's level of alertness as an invitation for interaction and connectedness. She held Chloe tenderly and rocked her gently. However, she did not seem to notice how her speech rate and volume was impacting Chloe. Chloe was recently weaned from oxygen to room air. However, changes in sound level often caused her to have difficulty maintaining enough oxygen in her bloodstream. During my observation, Chloe maintained an appropriate oxygen saturation level when the room was quiet. However, as the sound level in the room increased (i.e., nurses talking, activity in the room, and Cindy's excited rate of speech), Chloe's respiratory rate increased and her eyes closed until the sounds subsided. In this way, Chloe was demonstrating through her behavior that her physiological stability is fragile during stressful events.

The second observation took place shortly before discharge. Cindy was holding Chloe in her arms. As Cindy presented Chloe with formula via a standard nipple, Chloe readily opened her mouth and latched onto the nipple. After taking several quick sucks, Chloe started gulping, indicating a lack of control of the liquid bolus as the bolus got to the back of the mouth before the swallow response was triggered. As she continued to suck, milk started to drip from the corners of her mouth. Cindy continued to feed Chloe and did not remove the nipple; rather, she wiped the formula from her cheek. As the feeding progressed Chloe's respiratory rate increased even as Cindy continued to keep the nipple in her mouth. Eventually, Chloe's alarms began to sound, her breathing was particularly shallow, and her nares began to flare. The nurse approached Chloe's bedside and asked Cindy to give Chloe a break. Shortly after the nipple was removed, Chloe began to steady her breathing, although, she lay limp in her mother's arms, depleted.

Case #3: Grace and Aiden

Background. Grace is 29 years old. She defines herself as having a strong connection to her faith and her church. Grace spends much of her free time with family and lives within 20 minutes of her parents and siblings. She describes her family as very supportive in terms of both emotional and tangible support. Her social support scores on the NSSQ indicate that her perceived social support is within normal limits.

Grace's son Aiden was the most premature of all of the infants in the study, and required the most medical intervention and the longest length of stay in the NICU. Despite this, Grace remained focused on supporting Aiden during this journey. Grace reported that although the situation was incredibly difficult, her faith got her through this time in her life. Grace's scores on the mini-MASQ were within normal limits in the areas

of anxiety and depression. Her scores on the WMCI indicated that she had a balanced representation of her relationship with Aiden. Although she struggled to be able to describe their relationship, stating it was "too soon," her description of Aiden and this time in their life was balanced, acknowledging both the positive and negative. Grace was watchful of Aiden's behavior and even began to advocate for changes to his pain medicine based on her knowledge of him. It was clear that Grace was not only committed to Aiden, but that she recognized his behavioral signals and sought to understand and support his emotional well-being.

Pregnancy. Grace was shocked to discover that she was pregnant, and was initially nervous about sharing the news with her family because she was not yet married. However, both her family and her partner were very excited about the news. Within a month after Aiden's birth, Grace and her boyfriend decided to marry. They described this outcome as one of the positive impacts of her pregnancy. Grace explained that the pregnancy became real to her at about 9 weeks, when she heard Aiden's heart beat during her ultrasound. At 20 weeks Grace was delighted to learn that she was having a boy; her family was also thrilled, as everyone was hoping for a boy.

Themes from interviews with Grace. *Unexpected labor and delivery*. Grace was with her partner on the fourth of July, when she began to feel unwell. The next morning she awoke and discovered that she was losing blood. She immediately checked into the emergency room at her local hospital. Grace felt agitated and concerned because she was convinced that the hospital staff was withholding information from her. She stated, "when I finally got to the room, I just heard everybody whispering and stuff and nobody telling me anything" (Interview 1, p. 22). Grace eventually learned that she was

dilated and there was nothing they could do at the hospital to stop her body from continuing the birthing process. She felt terrified because "they didn't even have a NICU or anything, so if I would have delivered there, it would have just been it" (Interview 1, p. 23). She was eventually transported to Midwest Medical Center.

   Born at the threshold of viability. Grace was informed that her baby was "gonna come too soon," and she should "just spend the time that you can with the baby so that you know you were able to bond with him" (Interview 1, p. 23). It was explained to Grace that her son was on the threshold of viability and that the hospital has a policy to not perform heroic measures on children this young, as often the mortality risks outweigh the potential benefits. Grace recalls what she was told at the time:

> We can just do what we can for him and maybe you will have a day or two at the most with him. And even if he does make it he might have all sorts of developmental or psychological problems. He may not even know who you are. (Interview 1, pp. 23-24)

   Grace reported, "they never even thought they could resuscitate him, he was only 22 weeks…and they want you at 24 weeks before they even say you're viable" (Interview 1, p. 19). Eventually, Grace delivered Aiden. She reported, "I just saw his little arm moving. They just whisked him away, started working on him right away". He was "just one pound, and three ounces, and they said they won't give him much time, but I just saw he was just in there kicking his feet away…he opened up his eyes the first day as well, and that's what really got me" (Interview 1, p. 15). Grace tried to take things one day at a time, and each day Aiden survived gave her more strength. She stated, "So, it's like every time I look at him, I see he's still moving on after everything. So I'm like, if he's not giving up, I'm not giving up" (Interview 1, p. 14).

Alone on the delivery table, body feels broken. As the medical team whisked

Aiden away, Grace was left alone with her doctor on the delivery table. She was not able

to hold her baby, or see or feel her baby.

> I just see an arm moving and they just take him away. I see AJ (his dad), he's looking over there, he's hoping everything goes well. And I'm worried about him and then they're talking about how I have to deliver the placenta. I'm like oh my god. There's something else that I have to do. (Interview 1)
>
> I'm just praying that everything goes well with him. And they're giving me all type of pills so I can deliver the placenta, giving me more morphine. So finally – he's gone and it was another job to push the placenta out. And then they had to vacuum me because I guess some was still in there. So I'm going through all that. That was horrible.

Grace was so worried about Aiden that she sent her partner to go up to the NICU with

Aiden and the medical team. As she lay alone on the delivery table, Grace felt scared for

Aiden's health, frustrated that she is not able to be with him, and alone with a body that

felt broken (Interview 1).

"My faith has brought me through." She discussed her faith in God as a way of

coping with this unexpected experience, of having Aiden come so soon.

> Because even though the doctors are saying one thing, it's just like…it's been my faith, God that has, well…it has been my faith that has brought me through all of this. Even before delivery the doctors are telling me there's not really a thing that they can do. We just started praying, we just trust in God. This is my biggest fear that he would be sick or would come early, and it happened. But I know God has a purpose. (Interview 1, p. 18)

When Grace was in labor she asked to speak to the hospital chaplain. She stated, "that's

the only thing I could do, because this is crazy" (Interview 1, p. 19). Two weeks after

Aiden's birth, Grace reports that Aiden continues to defy the odds, "he keeps proving us

wrong." "He was so tiny…just one pound and three ounces, they said they won't give

him much time, but I just saw he was in there kicking his feet away" (Interview 1, p. 15).

The first time I seen him I was like he's a fighter. And everybody says the same thing. He's fighting through it because he's a miracle really. So that's how I look at him, my miracle baby, my fighter. (Interview 1, p. 14)

Grace interpreted Aiden's progress and survival to her faith, she reported, "It may look bad, but I feel like it'll be okay; you have to just trust God" (Interview 3).

Caregiving observation of Grace and Aiden. An observation of Grace caring for Aiden was not obtained because of scheduling challenges. Aiden had several medical complications and often had additional medical staff members at his bedside. During the week of discharge, another observation was attempted. However, shortly after I arrived at Aiden's bedside his primary care nurse informed me that the respiratory therapist had arrived to provide Aiden's parent with special training in how to use his respiratory equipment after discharge.

Grace is calm, observant, and consistent. She visits Aiden daily, yet she also makes time to care for herself. She knows Aiden as a person, and has learned from her experiences with him what his preferences are. She understands his behavior as meaningful and communicative. Her WMCI indicates that she has a balanced narrative of her relationship with Aiden. Grace described her relationship with Aiden using the following words: concerned, dedicated, and loving (Interview 2). After six weeks of Aiden's life in the NICU, Grace described Aiden as feisty, smart, particular, and determined.

Aiden is working to maintain physiological stability during caregiving. He relies on support to soothe himself during diaper changes and other caregiving tasks. For instance, Aiden benefits from having support to keep his arms and legs tucked during

caregiving. By supporting keeping his body tucked, he is able to maintain a steadier rate of breathing and thus, has more energy to open his eyes and be alert during caregiving.

Case #4: Lindsay and Bryce

Background. Lindsay is an 18-year-old high school senior who lives in a small town approximately 70 miles outside of Chicago. Lindsay lives at home with her mother and sister. Based on the mini-MASQ, Lindsay had unremarkable scores in terms of depressed or anxious moods. On the NSSQ, Lindsay had the largest support network in this sample, a total of 17 people. As a result, her scores were elevated by one standard deviation in both emotional and tangible support.

Although Lindsay did not complete the WMCI, based on two informal interviews and two observations the narrative she presented appeared to reflect a disengaged internal working model concerning her relationship with Bryce. Lindsay had difficulty describing her relationship with Bryce; she stated that she didn't know what to say. Her descriptions of Bryce were characterized by emotional distance and lacked specificity when compared to the other interviews. Further, Lindsay lacked emotionality when speaking about Bryce as she revealed limited affective tone based on her facial expressions and vocal inflection.

Pregnancy. Her pregnancy was unplanned and the father of the baby denied the baby was his. Lindsay's family was shocked to hear the news of her pregnancy, but they were supportive of Lindsay. Lindsay described learning about the pregnancy in this way:

> I was scared at first. I cried for a couple of hours when I found out I was pregnant, and then I just kinda like as I got farther along, I was like, 'I'm gonna keep him'. I'm gonna give him a good family with good family support and stuff. (Interview 1, p. 1)

Themes from interviews with Lindsay are limited, as she only completed two of three interviews. Also, Lindsay did not elaborate on the questions asked during the first and second interview. She seemed to struggle to provide detail as she answered questions in a nonspecific, rote manner. As the interviews progressed, she seemed to become irritated by the specificity of my questions. Once the date for the third interview approached, I called Lindsay to confirm the time, but she did not return my calls. After several attempts to connect with Lindsay by phone as well as notes left at Bryce's bedside, it became clear that Lindsay was no longer interested in participating in the study.

Themes from interviews with Lindsay. *Pregnant and still in high school.* Lindsay visits the NICU on the weekends as she is in high school during the week and she is determined to graduate on time. Shortly after the baby was delivered, Lindsay returned to school. She discussed this experience:

> No one even knew I wasn't pregnant anymore…It was overwhelming, because I was bleeding a lot. I wanna graduate, so I could get a good job for him…Yeah, I have to get my mind off of him being here, because he's gonna be here for a long time. I need to graduate so I could go to college. (Interview 1, p. 14)

Giving birth on the bedroom floor. When asked about when the pregnancy felt real to her, Lindsay replied, when "I had him on my bedroom floor" (Interview 1, p. 2). She described the delivery:

> I was only 6 months. You know I was cramping up earlier that night, but I didn't think anything cause my doctor said I was going to be cramping up so that I was gonna cry. So I didn't know I was in labor, and then my water broke. I ran upstairs and told my sister…she started freaking out because I was gushing blood…she thought I was miscarrying…and then I had him 15 minutes after that. I was really scared, but I was staying calm because my sister was screaming. (Interview 1, pp. 2-3)

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"I threw a blanket over him when he came out of me." After the delivery, the

ambulance arrived quickly:

> It was kinda stressful because I didn't know what was going on with him. When he came out I just threw a blanket over him with a towel, and my sister went to go unlock the door. But I really didn't get to see him until he was leaving. (Interview 1, p. 6)

Bryce was taken to a local community hospital, while Lindsay was placed in a separate

ambulance and taken to the same hospital. She did not see Bryce until the following day,

after he had been transferred from the community hospital to Midwest Medical Center.

Caregiving observation of Lindsay and Bryce. Lindsay was observed with

Bryce on two occasions. The first observation took place during the first week Bryce was

admitted to the NICU; the second interview took place two and a half weeks later. The

first observation occurred spontaneously, as I was not planning to conduct the interview

with Lindsay at Bryce's bedside. However, Lindsay was holding Bryce and she seemed

reluctant to leave. I later learned that she commutes two hours to see him, and she is only

able to visit Bryce on the weekends.

> As I approached Bryce's bedside, Lindsay was seated in a rocking chair with Bryce tucked inside her shirt. Bryce was wearing a diaper and had a blanket wrapped around his back, bottom and legs. Bryce's eyes were closed. His respirator rate and heart rate varied during the observation. Nurses spoke loudly in the background. I attempted to speak quietly with Lindsay so not to disturb Bryce or the other babies. Throughout the interview Lindsay spoke to me as she watched the monitor. When the monitor would beep, she looked at Bryce briefly and offered him a pacifier. (Lindsay, Observation 1)

During this interview, it was clear that Lindsay was nervous about harming Bryce during

caregiving tasks; she appeared anxious about Bryce's physiological stability as she

checked the monitor repeatedly. However, other than holding Bryce via skin-to-skin

contact, there was little warmth exchanged. Lindsay did not look at Bryce, speak to him, or touch his body other than to complete a task such as providing a pacifier.

The second observation took place approximately three weeks after Bryce was admitted to the NICU.

> As Bryce rested on his back in his incubator, Lindsay fumbled around to locate a clean diaper and wipes. She quickly lifted Bryce's legs, as his heart rate decreased and the monitors beeped. She proceeded to wipe his bottom as his body became limp. She continued to place a clean diaper under Bryce as he struggled to settle his breathing. As she completed attaching the diaper, she wrapped Bryce in a blanket and then the nurse positioned Bryce in Lindsay's lap. Bryce lay limp in her arms, depleted from the work of maintaining physiological stability during the diaper change. Lindsay noted that he is sleeping; she appeared pleased at his calm demeanor and began to chat with her sister. (Lindsay, Observation 2)

Case #5: Kara and Kiki

Background. Kara is a 21-year-old single woman who lives with her mother and grandmother in a western suburb of Chicago. Kara had an unplanned pregnancy within a causal relationship. During the interviews, Kara had difficulty expressing her ideas clearly and staying on topic. Additionally, when asked to recall specific memories, her stories were incoherent and sometimes difficult to follow.

Kara earned unremarkable scores on the mini-MASQ in anxiety and depression. Her perception of her social support system was also within normal limits. Based on the WMCI, Kara had a *distorted* internal working model of Kiki. Her relationship with Kiki seems to be characterized by a sense of longing for closeness, distancing, and disappointment. Kara described Kiki as feisty, sweet, and strong. She used pat, generic sounding descriptors when she referred to her relationship with Kiki such as it's "a positive relationship," "I really love her," and "it's really close." However, when asked

for specific memories that would support these descriptions, Kara was unable to provide

any specific events or experiences. Kara stated, "Yeah, we have fun. It's fun. I talk to

her and…I don't even know. I can't even think of any. I just know we have a really

close relationship" (Interview 2, p. 8). Although Kara was invested in her relationship

with Kiki, she also demonstrated striking insensitivity in her interviews. For example,

when asked to describe her daughter, Kara stated that Kiki looks like a chicken. When

asked whether she has any concerns regarding Kiki's development, she reported:

> I think her ear is so ugly because she always lays on it, so it's like bent up. I feel
> like that ear is gonna get ugly. Yeah. That's a setback for a girl. They can't be
> having ugly ears. What else? She's gonna get bed hair from all this laying down.
> So hopefully it grows right. (Interview 2, p. 11)

Another interesting aspect of this particular case study was that there seemed to

be a mismatch between Kara's expectations of caregiving in the NICU and the medical

team's expectations. According to Kara, she visited Kiki all the time because she wanted

Kiki to know she can count on her (Interview 3). However, when asked how often she

has visited Kiki in the past week, Kara reported about three times. While Kara felt that

she was visiting frequently, the medical team was concerned about Kara's limited

visitation, as she was not gaining enough experience in taking care of Kiki and was not

able to receive adequate support from nurses regarding feeding.

Pregnancy. She described her pregnancy with Kiki as very difficult. Kara felt

sick during the first trimester; she required hospitalization on three occasions secondary

to dehydration. Because she could not keep food or prenatal vitamins down, Kara began

to worry that something would be wrong with her baby. Kara missed several prenatal

appointments, including an ultrasound, because she was worried that they would find

something wrong with the baby; she appeared to be in denial about the pregnancy.

However, once she felt Kiki kick for the first time in September; the pregnancy began to

feel real. The quickening also helped to soothe Kara's fears about the baby's health.

Themes from interviews with Kara. The prominent themes of Kara's

experience in the NICU differed from the other women's accounts because Kara's

narrative tended to center around her own experiences rather than around her baby.

Kara's themes unfolded from not wanting the baby to deciding to keep the baby, from

feeling disconnected from baby to feeling connected with baby and then with family.

Finally, she demonstrated a transition in her understanding of herself as a mother, and her

ability to place her experience in the NICU in perspective.

Depressed about unplanned pregnancy. Kara was very upset when she learned

that she was pregnant, as she was not interested in having a long-term relationship with

her partner. Kara was particularly affected by the lack of stability in her relationship with

her partner because she grew up having a different father than her brother and she had

always envisioned being able to provide a more cohesive nuclear family for her own

children someday. Kara debated about terminating the pregnancy. However, her family

and friends convinced her to keep the baby.

> No, I didn't want to be pregnant. It was like, kind of the bright side is like, and I
> didn't want a girl. I wanted to have a boy, because I feel like it's a lot with girls,
> but it was like, "Okay, at least we can do stuff together and I know I'll have
> support," but as far as my relationship, I didn't know how that would go and I
> always, like, because my mom, like, I have an older brother and we have different
> fathers and I don't want that same thing to happen, and it's just like, I didn't really
> mind having a baby, it was just the time-frame and who I had it with. And then
> with me being sick, it's just like, that really made it hard and I was just like, "I
> really don't want to be pregnant."

Unexpected labor/delivery. When Kara was 21 weeks pregnant she went to an ultrasound appointment and learned that she was dilated. She was encouraged to limit the time she spent on her feet. A month later, Kara began spotting. She was admitted to the hospital for further monitoring, as she was continuing to dilate. Later that week, it was determined that she was going into labor, a C-section was given, and Kiki was born at 25 weeks.

> They were already monitoring me because they said her heart rate was something, I forget, and then I started having cramping, and then they were like really really monitoring and they said I was having contractions. I just remember I just, I remember feeling really wet, and then I looked and I was actually bleeding, and that's when they came in and everything, and they were like, I was five centimeters. And I remember the doctor told me before that she was only 25 weeks so I don't have to get to 10 centimeters for me to deliver. And then when I first came in on that Monday they said she was head down, but when they checked again she was breech, so they had to do a C-section. So then all that started happening. (Interview 1, p. 1)

Kara described her fears as she lay on the operating table:

> I was so scared, because before I kept asking, "Is it going to hurt? Is it going to hurt?" And I was so anxious, and then, because like I said, I had heart problems. Well, I had a heart problem. I couldn't get just a regular epidural. They had to give it to me gradually. So I got stuck in my back like this 10 times, so that's hurting, and just so much, and I had to have two IVs and something here for my blood pressure and they tape your hands down and there's just so much going on, and I was just like –
>
> I was asking a million questions. I was like, "You're not starting?" And they're like, "We're not going to start until you're comfortable." I was really anxious, like very, very, very, anxious. And then I was just very scared. I was scared it was going to hurt, and then I was scared like, "Is she going to be ready to come out?" I was just scared at that point. I was really scared. And then, but they wound up putting me to sleep towards the end when they were sewing me up, because that's how anxious I was. Really, like, "Are they done? What are they doing?" I mean, like when they took her out, I couldn't see her but I could see where they were with her and I told him I was like, "Go look at her." It was just so much going on. (Interview 1, p. 1)

Baby doesn't feel fully human. Kara recalled her thoughts and feelings as she

was waiting to meet Kiki for the first time:

> So I was really anxious and I was telling everybody, I was like, "Do not show me
> any pictures. I want to see her for myself face to face." I was just really scared,
> like, "Something's going to be wrong," like she wasn't entirely finished
> developing or something or had like a deformity. I was really scared. (Interview
> 1)

When asked to describe Kiki, Kara expressed her surprise at her baby's prematurity:

> She's so tiny, but how would I describe her? I know it's not right, but at first I
> was like, "She looks like a chicken." I said that at first. "Why does she look like
> a chicken?" But no, I feel like she's like me, like I said, like, she probably gets
> irritated a little easily or she's just, I can say like me and her probably like to sleep
> a lot. Of course newborns are going to sleep a lot anyway, but I can just tell she's
> just in her own zone sleeping and she's so pretty and I know she's going to have
> nice hair, and she's just a little tiny fragile little thing. I think she's strong. I
> think she's a fighter.

Throughout the first and second interviews, Kara seemed to struggle with whether

to think of Kiki as fully human yet. She often referred to Kiki as "it" rather than "she",

although by the third interview she began to use the pronoun "she" or refer to Kiki by her

name. Kara recalled how she first thought of Kiki:

> She's so early. I didn't think she was done. I didn't think all of the regular things
> like hands, feet, and face would be developed. And I expected to see webbed
> hands… she seems more human now, like a real baby. (Interview 3)

From foreign baby in a foreign environment to my own baby. Not only was

Kara uncomfortable with Kiki's appearance, she was also anxious about how she could

interact with Kiki because she was physiologically so immature:

> Well, like when she was born, I was really, really scared. And I think that's when
> she was under the lights because her skin was jaundice. And then they had her
> humidity in there at like 100 percent. So it was always foggy. And so it's just like
> – they were like be careful. Don't rub her because of her skin. It was just so much
> like don't rub her or don't try and have the door open so long because we want to
> keep the heat in or just this. It was just like so much. And by her being so small,

I feel like she's so fragile. And she still is because her body is immature. So it kind of – I try to be very, very careful. (Interview 3)

Kara recalled how she doubted her own ability to care for Kiki without hurting her:

I feel like with a baby, you have to be careful period. But it's like extra careful like making sure she's okay and comfortable. And I don't want to – because I'm heavy handed. And I don't want to just have my hands resting on her, putting pressure on her. It's a different type of interaction because she's preemie. And just like certain things like I know she jumps a lot and [00:20:14] [inaudible] her body. It's just something – she's a preemie. It just goes along with it. (Interview 3)

Kara also felt that the medical equipment which was necessary to sustain Kiki's life also created a physical and emotional barrier between the two of them:

Just feel like she's boxed up. I know she has to be in there to keep her warm and everything, but it's just, I just see some of the babies have like cribs and little basinets, so it's kind of like, I see some of the moms getting to hold their babies longer, but I know she has to stay warm, but they had her humidity up really high at first where it was so foggy, and keep wet and keep wet, and they had to keep it like that for her. (Interview 1)

A sense of helplessness began to set in, as Kara was unsure of what else she could offer to Kiki:

I feel like besides helping take her temperature and holding her, I feel like there's really nothing else I can do for her. I mean, I know they say you can, like, bring in blankets and stuff to put in there and breast pumping and, you know, stuff like that. I can do stuff like that. But because of the incubator and all of the wires, they just get in the way of a lot of stuff. (Interview 1)

As Kiki continued to mature, she began to look more like a full-term baby, her physiological stability improved and she required less equipment to support her. The removal of these barriers facilitated more interaction between Kara and her daughter and lessoned Kara's anxiety.

It's better. It's easier to move her around and hold her. And I know she was uncomfortable because, at one point, she had a lot of planks. Not planks but all of that attached to her arm. And she was probably irritated and couldn't really move.

So it's gotten better. I can hold her better. And I know she can move around. So I can feel that she feels better without all that stuff on her. So that makes me feel better…but since she's progressing, she's able to keep her temperature better, so she's able to come out more. Yeah. So I'm getting to bond more with her, getting to know her better. And when she was first born, you'd see all her blood vessels. And it's like she just looks different but in a good different. (Interview 3)

Eventually, Kara began to feel that Kiki was her own baby. As she continued to feel more comfortable caring for Kiki, she gained more experience with her and began to feel close to her and even dream about their future together as mother and daughter.

That's my baby. I love her. I really do. Every time I'm with her and just thinking about her, I just think about our future and just I feel like that she's going to be a really smart girl, really little, feisty, little, smart girl. And I feel like this little thing right here is just a bridge she has to get over. I feel like she got this. She's going to get through it. And I just feel really content with her, even though I know I wasn't ready for a baby. It's difference once they're born. You're like oh my God, this is my baby. But when I was just out there, I was thinking like I made this. This was inside of me. And I just really do love her a lot. (Interview 3)

Jealous of baby's relationship with dad. Kara struggled with feeling jealous of Kiki's relationship with her father (Jay); she feels that Kiki is more responsive to Jay. She suspects this is because she is doing something wrong.

I was thinking at first, I was like, "I don't think she likes me," because when her dad comes around she's eyes open and all of that and playing with him, but with me, it's like she's asleep. And I'm like, "So you don't like me?" But yeah, just her responding to me, like earlier when I had to go to the bathroom I'm like, "I'll be back." I'm like, "Blink once for yes," and she kind of blinks, and I'm like, "Okay, I'll be back." (Interview 1)

Well, for one, she loves – her dad, he always like – she loves to squeeze on his fingers and stuff. She knows. Like let me try to touch her and stuff, she knows. But when he comes around, she knows him and squeezes his finger. She knows that's her dad. (Interview 3)

Kiki's father, Jay, has a calm demeanor. He visits Kiki approximately five days per week. Each time I was in the NICU, I noticed him holding Kiki skin to skin, inside his shirt. Kiki's body looked relaxed; her respiratory rate remained steady as she

snuggled with her dad. On several occasions, I noticed that Jay and Kiki lay together cuddling for an hour. Unfortunately, I was unable to obtain IRB approval to interview any other family or medical team participants.

Baby brought everyone together. Kara was pleased to see that she and her boyfriend were growing closer and that his family was becoming involved in Kiki's life from the start.

> Yeah. And I know they always care and everything. But it's getting a lot more support since she's been born. And it's definitely changed the family dynamics on his side of the family because he was even just saying last night like she's opening a lot of doors. Kiki is opening a lot of doors for us. So some that we probably would have to kick down. So it definitely has – I feel like it's bringing us to a family. It's like my mom comes up here, and his mom comes up here. And it's just like family.

> Because when she had her surgery, his mom was just thinking we'll put all our differences aside because it's about her. And we just have something bigger. And then when I was in the hospital, and his mom came and saw me, I was surprised. So it's just like – like I said, she's bringing everybody together. So it definitely changed the family dynamics. (Kara Interview 3, pp. 21-22)

> *Making meaning in an unfamiliar context – "I became a mother in the NICU."*

Over time, as Kara grew familiar with the NICU, the equipment, and the medical terminology, this became a way of life.

> (Going to the hospital) became a normal thing. Like I said, it's not normal…but it's become normal now. People that don't really know you are like, "what are you going to the hospital for" I'm like, "to see my baby"…It's normal to me now. (Interview 3)

Kara began to develop an understanding of what her role is in the NICU:

> Yeah. I feel like if I'm not giving her love, or if I'm not here to see her or support her, then I feel like, on my part, that's not being a good mother…I'm trying to make her as comfortable as can be, even if it makes me be uncomfortable or try and make sure she's good and everything is okay with her. And she's coming first regardless of what's happening and going on with me. And yeah, just not just plopping her on my chest or whatever. I'm like are you comfortable? Is the

breathing tube right? Are you okay? Just trying to make sure my little baby is okay. Or just checking her, making sure she's clean and everything and changing her diaper, making sure it's on right. And the tube in the back is not pulling on her neck…I'm not just oh; let me hold her or whatever. I'm making sure she's comfortable. I'm just trying to be the best mom I can be to her and make sure she's relaxed and content and she feels the love. (Interview 3)

When asked if being in the NICU has changed Kara as a mother, she responded:

Yeah, it definitely has because I feel like if you have a baby in the hospital, it's a harder experience. You don't have that direct contact. And I feel like it's brought me closer to her. I feel like we will still be close if she came normally at 40 weeks and went home. But I feel like it brings me closer. It gives you a better vibe because it's like I knew she was sick and everything. It's like I was just – like me and her dad, we were saying either one of us, in a heartbeat, will take her place in incubator if we could. We would take her place in a heartbeat.

And I feel like it's going to make me a stronger mother towards her and know more of her needs and what she likes and how she's going to interact and just everything. I feel like this experience definitely makes you stronger, and it's different because, even his mom was saying, I never had that experience. All my babies came home with me. And a lot of people – that's why I'm saying, people say it's going to be okay, but they'll never know this experience unless they go through it. (Interview 3)

Caregiving observation of Kara and Kiki. Kara is cautious when caring for Kiki. She is also responsive to support from nursing regarding feeding.   She notices Kiki's respiratory rate changes during feeding and considers positioning. However, she does not interpret Kiki's behavioral cues as communicating that she is uninterested or not ready for the bottle. When mom presented the bottle, Kiki turned away; Kara then pressed Kiki's lip down and placed the bottle in her mouth. Kiki's mouth filled with milk, she could not manage the bolus and began to change color, her heart rate dropped, and her nares became pale. Kara became worried and stopped feeding immediately.

Kiki has normal muscle tone. She is now on room air and is beginning to eat by mouth. She struggles to maintain a steady respiratory rate when drinking from a bottle.

During the observation, Kiki seemed fatigued, she kept squinting her eyes as an overhead light shined brightly above her head. The nurse had turned on the light so that mom could see Kiki's color clearly during the feeding. Kiki kept her arms and legs at midline. She was swaddled, however was able to free her hands in order to suck on her fingers periodically.

Before the feeding began, mom held Kiki cradled in her arms. Kiki was watching her mother's face carefully and Kara was speaking softly to Kiki. Kiki's muscle tone was relaxed; she was in a quiet alert state. During that time, Kara spoke about how anxious she felt about feeding Kiki; she was particularly nervous about the possibility of Kiki coming home with a feeding tube.

Table 12. Summary of Individual Themes

Mother	Themes
Patty	• Unexpected labor and delivery • Few opportunities to be with David first few days after birth • Nurses as providers of social support • Baby in a glass box • Caregiving tasks build the relationship
Cindy	• Pregnancy complications become life threatening • Too sick to be really present to meet baby • "Was I really pregnant?" • Disappointed that things are not going as expected, but trying to stay positive • Pumping breast milk as caregiving • Need privacy and more time together • Impact of NICU on Cindy and Chloe
Grace	• Unexpected labor and delivery • Born at the threshold of viability • Alone on the delivery table, body feels broken • "My faith has brought me through"
Lindsay	• Pregnant and still in high school • Giving birth on the bedroom floor • "I threw a blanket over him when he came out of me"
Kara	• Depressed about unplanned pregnancy • Unexpected labor and delivery • Baby doesn't feel fully human, "Baby looks like a chicken" • From foreign baby in a foreign environment to my own baby • Baby brought everyone together • Making meaning in an unfamiliar context – Becoming a mother in the NICU

CHAPTER V

RESULTS – ACROSS CASE ANALYSIS

Introduction: Themes Across Cases

Multiple case studies provide an opportunity to examine the phenomenon of

becoming a parent in the NICU from an individual perspective as well as by exploring

similarities and differences that occur across individuals. This methodology enables the

researcher to look beyond the individual case and to examine the phenomenon of

mothering in the NICU. In this way, the cross case analysis highlights the "most

important experiential knowledge" (Stake, 2006, p. 44) by focusing on collective

experiences rather than specific experiences within an individual case. In this study,

three overarching themes continued to present themselves: (1) trauma as the backdrop to

each woman's experience of becoming a parent in the NICU; (2) caregiving builds the

relationship between mothers and their newborns; and (3) protocol-based care interfered

with the mothers' ability to engage in caregiving.

Trauma was the Backdrop of Each Woman's Experience as a Mother in the NICU

Each woman entered the NICU having experienced an unexpected traumatic labor

and delivery as well a prolonged separation from her infant after birth. The extreme

stress of preterm birth was compounded by the strangeness of the NICU environment,

which seemed to have its own language, culture, and equipment. Preterm birth was

experienced not only as a shattered expectation of birthing a healthy infant, but also as an

abrupt end to pregnancy and a loss of maternal role. As a result, both the infants and

mothers were stuck between the womb and the world. The infants struggled physiologically to stabilize their immature internal system in order to function without the safety of their mothers' womb. The mothers struggled with an onslaught of intense feelings including shock upon seeing their preterm infant, disengagement from their infant, disorientation to the environment, disappointment that their bodies could not complete a full term pregnancy, guilt that they must have done something wrong, and helplessness as they watched their infants struggling and could not protect or comfort them. They felt ineffective and disconnected from their role as mothers. Further, their preterm infants had very specific needs for caregiving and support, which prevented the mothers from being effective caregivers early on. Ultimately, their inability to protect the infant from pain and limited opportunities for closeness seemed to further increase the strain on the mother-infant relationship and sense of alienation for the mothers.

Shocking labor and delivery. The parental experience of preterm birth has been described as a moment of shock (Muller-Nix et al., 2004); new mothers may find it impossible to think, and they may experience numbness, confusion and disconnection. In the present study, all of the participants experienced an unanticipated, frightening labor and delivery. However, Grace and Lindsay's experiences best illuminate how quickly each situation unraveled.

When Grace was 22 weeks pregnant she was attending a family barbeque over the fourth of July. She began experiencing significant abdominal cramping and was quickly rushed to the hospital. Just 48 hours later, she had given birth to an infant who was on the threshold of viability. The medical team informed her that they could not make an

effort to resuscitate her baby, as he was too premature to survive. Despite very little

medical support, David did survive.

Lindsay, an 18-year old high school student, also went into labor unexpectedly.

She reported that she was home alone with her 20-year-old sister, when she began

experiencing intense cramping. She did not realize she was in labor, she thought the

discomfort was typical in pregnancy, so she went to bed for the night. She awoke at 4:30

in the morning in active labor. Lindsay recalled:

> I had the baby on my bedroom floor, my 20 year old sister delivered the baby…it
> was like 4:30 in the morning when my water broke, and then I had him 15
> minutes after that. I was scared, but I was staying calm because my sister was
> bawling her eyes out. (Lindsay, Interview 1)

Prolonged separation. In addition to experiencing an abrupt and unexpected

birth, the women experienced prolonged separation from their infants after the baby was

born. All of the infants needed immediate medical care to stabilize their physiological

systems. Most of the women watched in horror as their tiny infant was removed from

them on the brink of death. The women also required medical attention, which ranged

from completing delivery of the placenta, to abdominal stitches, to requiring intensive

medical care. All of the mothers and infants were forced to function without each other.

> I saw her when she came out. But then I still had to go back in ICU and I was still
> on –magnesium, I can't remember. I felt like I was on that for a while so I
> couldn't move. I couldn't like get up and use the bathroom, I couldn't do
> anything, I just had to lay there until the 24 hours was up. So then I was stuck in
> bed and still couldn't see her. So that was just like a fresh new experience
> because I was stuck there. I wasn't able to see her until like half way through the
> next day because I was on the magnesium until 7:00 or 9:00 on Saturday morning.
> And so it was just frustrating because I wanted to see her again. (Cindy, Interview
> 1)

One of the women had to drive to a major medical center in order to see her baby for the first time. After giving birth on her bedroom floor, Lindsay watched her baby as he was taken to a community hospital by ambulance. She was then taken to a hospital for care as well. The next time she saw her baby was the following evening when Lindsay drove to a major medical center located two hours from home.

In addition to the infants and mothers medical care delaying reunion, sometimes NICU visitation schedule further delayed the mothers' reunion with their infants:

> They would not let me see him until pretty much (until the next morning)—this area is closed from 9:30 am until 12:00 pm. I was waiting for my nurse to come in, but the shift was switching. She came in 15 minutes to closing time here. She said, "You can't go until you eat something, but if you eat something and you're just throwing up—" It was just a terrible cycle. They did bring me here somehow 10 minutes before 9:30, so I got to see him for 10 minutes. That was pretty hard to see him the first time. I was really mad I didn't get to see him earlier too. I was waiting for my nurse to come in since 6:00 in the morning. (Patty, Interview 1)

The delayed reunion between mothers and their babies also resulted in family members getting to meet the baby prior to the mothers. For Kara, this was particularly hurtful as she was left alone in her hospital room.

> So everybody went up there and then after that they left. The only person who came back to my room was him, and then we went to sleep and then I woke up the next morning, he took me up there to see her. I didn't get to see her until the next day. (Kara, Interview 1)

Not only is a traumatic delivery and prolonged separation from the infant an extremely problematic beginning to the mother-infant relationship, it is possible that this separation may place mothers at risk for developing post-partum depression (Righetti-Veltema, Conne-Perreard, Bousquet, & Manzano, 1998). For some women, the separation from their newborn was the most stressful aspect of having a critically ill

infant (Miles, Wilson, & Docherty, 1999). Postnatal psychological distress of mothers may have an effect on the mother's interaction with her newborn (Muller-Nix et al., 2004; Wijnroks, 1999), may produce struggles with bonding with the infant (Feldman, Weller, Leckman, Kuint, & Eidelman, 1999), and may also have long term effects on the parenting of the preterm child.

Feeling cheated. All of the participants struggled to cope with a variety of losses during the first few days after birth following their newborn's admission to the NICU. One month after the birth of their infants the new mothers felt resentful, as they tried to reconcile shattered dreams and make sense of their new reality. For example, Cindy and Grace discussed how they had to reconcile the real birth with the birth they had imagined. As Cindy said, "Yeah, you expect to hold your baby and all that, but it wasn't…I missed that" (Cindy, Interview 1). Grace also recalled her feelings after delivery, "I was like where is my child? Because I hadn't seen him as of yet, I was feeling cheated because everybody else got to see him except for me" (Grace, Interview 1). Patty and Kara felt unsettled by their pregnancy ending so quickly and abruptly. Patty reported, "I'm still not ready, I feel cheated; I wasn't ready to have him outside of me". Kara just learned she was pregnant a month before she delivered Kiki. Kara lamented, "I barely got to live with that and then I found out I was dilated" (Interview 1).

Shock of seeing their preterm infant. Once the participants were reunited with their infants, they had to cope with the shock of seeing their infants. When asked about this experience, Lindsay reported, "I didn't think he was mine. I guess it took me a while" (Interview 1). In contrast, Grace recalled a sense of amazement when she saw her newborn for the first time:

He was so tiny and precious. I'm like "oh my God". This is him, he's really here. That's all I could keep saying. As I mentioned, everything just went so quickly…I never really cried. I was just in shock by everything. It didn't really hit me until when I was actually discharged from the hospital and I had to leave without my baby. (Grace, interview 1)

The participants also were frightened about what prematurity means for their infant. Two of the participants seemed to hold their infants at an emotional distance. For example, they described their infants in a depersonalized manner by referring to their infant as "it".

I was just really scared, like, "Something's going to be wrong," like she wasn't entirely finished developing. I was really scared… (I thought) she looked like a chicken. (Kara, Interview 1)

I didn't have time to think about it. I was hoping it would just stay alive, because of how early it was, I was kinda scared that he wasn't going to. (Lindsay, Interview 1)

Upon seeing her baby for the first time in the NICU, Patty was immediately struck with feeling powerless. The baby seemed so different to Patty. She assumed he had different sensitivities and required a different type of caregiving from a full-term baby. The incubator and her son's special needs served as a barrier to her feeling connected.

I know at the beginning it was really hard because I couldn't talk to him and he was just kind of laying there…I couldn't touch him too much because his little system is not developed yet…I guess it (the incubator) is like a little glass bowl, my last name is on there, so I guess he's mine, right? (Patty, Interview 3)

Patty's experience of disconnection and anxiety resonates with the findings from Feldman et al. (1999), who noted that mothers who are highly anxious and have a sick newborn are at highest risk for disturbances in attachment. In fact, mothers with a history of anxiety are particularly affected by the separation from their preterm infant after birth, as separation disrupts the attachment process and impedes the mother's ability to care for her medically fragile newborn (Hughes, McCollom, Sheftel, & Sanchez, 1994) **others**

were devastated when they were discharged from the hospital without their infant.

After a few short days of hospitalization, the women were discharged from the hospital, which forced the participants to cope with an even greater separation from their infant. The discharge not only imposed a tremendous emotional stress, it also overwhelmed the participants with various barriers to seeing their infant. For instance, the participants needed to coordinate transportation, cope with excessively long commute times, and balance their work responsibilities and schedules. Being discharged from the hospital forced the participants to confront their new reality: they had given birth to a preterm, medically fragile infant who will not be coming home with them. They had to make plans for their new future such as adjusting maternity leave (all of the women took their leave after the infant was discharged from the hospital) while simultaneously resuming life responsibilities such as paying bills, keeping homes clean, planning meals, and returning to work. This separation was unexpected for the mothers, as they had not recovered emotionally from delivering a preterm, critically ill newborn:

> I really wanted to cry…and I guess I was still in shock, running off adrenalin and just off of everything that happened, so my mom's like "you ready to go?" They did let me stay an extra day, but I could be asking to stay all week. (Grace, Interview 1)

> I did not get much contact until they kicked me out of the hospital, essentially. It was a Sunday. I came to say goodbye, and I just started bawling. (Patty, Interview 1)

The participants referred to this separation as yet another loss they were expected to cope with. One participant (Cindy, Interview 3) expressed frustration that the medical team did not appreciate the major upheaval that was involved in arranging daily visits for

working parents. Grace also reported that she felt remarkably fatigued going to work during the day and rushing to the hospital at night so she could be with her baby.

Feeling helpless. One of the most difficult experiences for the women in the study was feeling powerless, particularly in relation to protecting their infants from pain. Based on a meta-analysis of 14 studies that investigated parental experience in the NICU, Obeidat, Bond, and Callister (2009) found that the inability to perform a normal parenting role, such as caring for an infant who is in pain, is a predominant source of distress for most NICU parents. All of the participants spoke about feeling helpless, as they could not protect their infants from pain and uncomfortable medical procedures. For instance, Grace stated, "I'm still helpless in a way, because I really don't know what to do for him" (Grace, Interview 1). Some participants also expressed a sense of alienation and loss of control:

> I watch him in a glass box, and see everybody else take care of him because they know better. Here I am sitting clueless kind of observing and not knowing anything. I don't get to take him home and he's not really anybody, it feels like he's not a little person. (Patty, Interview 3)

For Kara, helplessness struck her in a different way.   She was first absorbed by how frail her daughter seemed, she seemed to link her daughter's fragile appearance to her own inability to carry a pregnancy to term. Kara recalled, "she was so tiny and just helpless, it's not a good feeling being up here (in the NICU)" (Interview 1).

Summary. The magnitude of the crisis of preterm birth is consistent with the American Psychological Association's definition of trauma. The *Diagnostic and Statistical Manual of Mental Disorders,* 4th edition, Text Revision (*DSM-IV-TR;* American Psychiatric Association [APA], 2000) specifically defines a trauma as:

The direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate (Criterion A1). The person's response to the event must involve intense fear, helplessness, or horror (or in children, the response must involve disorganized or agitated behavior) (Criterion A2). (p. 463)

It is not surprising that parents of premature infants can experience a host of psychological challenges such as anxiety or depression (Maloni et al., 2002) as well as ambivalence about the baby's survival (Easterbrooks, 1988). Likewise, caring for a medically fragile infant with an uncertain outcome may result in re-traumatization and prolonged hyper arousal for parents. In fact, mothers may continue experience these symptoms even two years after the infant's birth.

Researchers have begun to document traumatic parental reactions in the NICU as acute stress disorder (ASD), which can be evident during the parents' early visits to the NICU (DeMier et al., 2000; Karatzias, Chouliara, Maxton, Freer, & Power 2007; Lasiuk, Cormeau, & Newburn-Cook, 2013). Parents may present with: (1) derealization – trying to function in an unfamiliar and confusing NICU context; (2) denial – unwillingness to accept what has occurred; or (3) dissociation – difficulty processing information because of tremendous fear and shock (Dyer, 2005, p. 42). ASD symptoms may emerge within the first month of the traumatic event. If symptoms persist beyond this time then a diagnosis of post-traumatic stress disorder (PTSD) may be assigned. According to the APA (2000), PTSD symptoms may include: (1) re-experiencing the event via intrusive thoughts; (2) avoidance of activities or other stimuli that may represent the event or

trigger memories of the event; and (3) increased arousal, which was not present before the event.

Studies have shown that as many as 23% of mothers of highly preterm, hospitalized infants meet criteria for acute stress disorder (Feeley et al., 2011; Vanderbilt, Bushley, Young, & Frank, 2009), and 41% of parents in the NICU exhibit symptoms of PTSD, even 14 months after birth (Pierrehumbert et al., 2003). Furthermore, several studies indicate that mothers' psychological distress following a preterm birth did not improve even years after delivery (Holditch-Davis et al., 2009; Huhtala et al., 2014). In their study evaluating the long-term contribution of very preterm birth on parental mental health, family functioning and parenting stress, Treyvaud, Lee, Doyle, and Anderson (2014) reported that at seven years following birth parents of very preterm children were more likely to report moderate to severe anxiety levels, high depression symptoms, as well as less optimal family functioning. In a qualitative study conducted by Garel and colleagues (2007) one year after preterm delivery, mothers continued to suffer from depressed mood, "social isolation, feelings of persecution, self-depreciation and withdrawal," along with post-traumatic symptoms, such as re-experiencing the event and avoidance of activities that may trigger memories of the event. For most of the participants, the baby's birthday also served as another trigger. Another study (Latva, Korja, Salmelin, Lehtonen & Tamminen, 2008) found that mothers' memories of negative birth experience as well as the appearance of the preterm infant were correlated with their child's emotional and behavior outcomes seven years later.

Maternal psychological well-being impacts the child's social and emotional development. Mothers of preterm infants have been observed to be more controlling,

intrusive, and less sensitive in their interactions with their infants (DiVitto & Goldberg, 1979; Feldman & Eidelman, 2006; Muller-Nix et al., 2004) than mothers of full term infants. Further, intrusive interactions with infants have been noted to lead to disrupted attachment relationships, difficulties with social emotional regulation, as well as behavior problems in longitudinal samples of preterm infants (Avan, Richter, Ramchandani, Norris, & Stein, 2010; Huhtala et al., 2014).

In summary, having an infant in the NICU was an overwhelming experience for all of the participants. The woman experienced a traumatic labor and delivery, which resulted in a truncated pregnancy, and a curtailed psychological space to prepare for their role as mother. They endured prolonged separation from their infants and eventually had to leave their infants behind in the hospital when they were discharged home. All of the women suffered from considerable emotional distress seeing their newborn infants subjected to numerous uncomfortable medical procedures. Further, medical equipment such as incubators, central lines, and breathing tubes prevented mothers from gaining physical closeness with their infants. Feelings of helplessness ensued as they struggled to find a way to care for their infants in such an unusual circumstance.

These findings are in line with other studies that have noted traumatic delivery and separation from the infant as tremendous stressors for mothers (Miles et al., 1999; Righetti-Veltema et al., 1998) because they disrupt the mother's ability to actively participate in caring for her infant and getting to know her infant. Both quantitative and qualitative studies (Affonso, Hurt, Mayberry & Haller, 1992; Holdistch-Davis & Miles, 2000; Miles et al., 1999; Montirosso, Provenzi, Calciolari, & Borgatti, 2012) have

documented loss of the maternal role as caregiver and protector as the primary source

stress for mothers of very low birth weight infants in the NICU.

Caregiving Builds the Relationship

Despite the considerable challenges mothers encountered in understanding their

infants' communicative behavior and responding contingently, all of the participants felt

that engaging in caregiving was the primary means of building their relationship with

their newborn. This experience has been further supported by ethnographic and

phenomenological studies of mothers in the NICU. Heerman et al. (2005) showed that

mothers evolved from being an outsider to being an engaged parent along four continua:

focus from NICU to baby, from their baby to my baby, from passive to active caregiving,

and from silent voice to advocate.

Mothers were afraid of hurting their baby. All of the participants benefitted

from opportunities to care for their infant. At the outset of the hospitalization all of the

participants felt helpless and unsure of how they could support their infant. Grace recalls

this time as particularly trying because her extremely premature infant was particularly

fragile:

> He can't even cry, so it's really intense. You never really know what the right
> move is, especially since he's so tiny and critically ill. My fear is that I'm going
> to do something that I'm not supposed to do. (Grace, Interview 1)

Each mother struggled with feeling afraid of hurting their infant. Lindsay recalled, "I

was so scared I was gonna break him…he was so teeny. I was freaking out; I didn't want

to break his leg or something (Lindsay, Interview 1). Kara was intimidated by the

medical equipment:

Well, like when she was born, I was really, really scared. And I think that's when she was under the lights because her skin was jaundice. And then they had her humidity in there at like 100 percent. So it (the incubator) was always foggy. And so it's just like – they were like be careful. (Kara, Interview 3)

Role of nurses as facilitators of caregiving. During the first few weeks of hospitalization, the participants reported that their fear of harming their baby led to feelings of helplessness. Almost all of the women required encouragement to begin taking care of their baby and engaging in basic caregiving tasks.

I think I'm personally scared that I might harm him, but I can say the nurses have been helpful. They asked me if I wanted to bathe him yesterday and just help out a little bit. So I'm like okay, this something that I can at least start doing with him. (Grace, Interview 1)

When reflecting upon her experience in the NICU during her son's discharge from the hospital, Grace recalled that the nurses were particularly helpful in encouraging her to begin caregiving:

I would say maybe just his primary nurses that he's had even when I was scared to do things; they just kind of throw you out there. They're like, "come on help me do this," and so the more that I interacted with him the more I became comfortable with doing. (Grace, Interview 3)

Kara relied on the nurses as a resource about preterm infant development:

The nurses, they're really nice and they're really helpful. They make it a little better. You know, just let me know a lot of things are normal for like preemies or for newborns and things, they're really helpful and informative and they answer questions and give a lot of information. (Kara, Interview 3)

For Patty, the instruction she received from nurses was very helpful as she had very little social support from her family and friends. She reported that it was through the support that she received from the nurses that she felt emotionally ready to be with her son. In Patty's case, she felt supported on many levels from the nurses: she discussed the physical support she received to assist her body in recovering from birth, practical

support to help her understand how to care for her infant, and emotional support to help

her feel less alone during this frightening time.

> I was stuck in the ICU for a week; they would just come in to each lunch with me or breakfast with me because I was there alone a lot of times. So these are the nurses that actually made me survive there…they're wonderful people. They're teaching me everything, showing me what to do, everything, making it more comfortable [inaudible] which is kinda necessary, since he's going home soon. At least one nurse that sat with me and told me all the little ends and outs of the tricks that she's known and she's used since she was a mom, and now she's a grandma. So she told me all those little things – if this happens you can do this and this happens and you can do this. And if I needed help with burping him she'd help me and tell me which position to put him in. (Patty, Interview 3)

Over time the women became more familiar with how to care for their infants and they

felt more confident:

> I feel a lot more comfortable as he's more stable now. Before like I said in the beginning he was on the ventilator, so tiny, I was very nervous to even touch him. They don't want you to caress him or anything but just hold your hand on him firmly. And to be honest my biggest fear was always was like little small babies – newborn babies even like I went through them six months if I could just pick him up. So this was really out of my comfort zone, and as he steadily progressed, he got bigger, and just able to tolerate more things. I felt more comfortable to hold him. (Grace, Interview 3)

> I was scared to change her diaper because she's so tiny and I don't want to hurt her. I'm just a little scared and like when I first held her I was really, really scared. I don't want to break her or hurt her. I'm getting a little bit more used to it now. (Kara, Interview 3)

Pumping breastmilk as caregiving. During the beginning of the NICU

hospitalization, pumping breastmilk was one of the few activities mothers were able to

engage in to help their infant. All of the women felt motivated to help their infant in this

way. For instance, Cindy reported that pumping breast milk was one of the few things

she could do for her daughter while she was in the NICU. Cindy seemed to channel all of

her energy into doing this task well; her goal was to produce enough milk so that Chloe

would not need to receive any formula as supplements (Cindy, Interview 1, p. 26). Grace

explained her experience in this way:

> After I was discharged from the hospital, I received a pamphlet about prematurity.
> It talked about how you may feel helpless, but the one thing you can do is provide
> the baby with your milk. So really it was no question if I was going to pump or
> anything then because I had to – this is the only thing can physically really even
> do for him. So yes. (Grace, Interview 1)

Despite their motivation to support their infants by providing breastmilk, all of the

women eventually became overwhelmed by the task of pumping while their infants were

in the NICU:

> It's like, oh, it's time to go pump again. I'm just dreading it. I feel bad, but you
> know, you have to do it, so you do it anyway. So it's not necessarily something I
> look forward to doing. But I think it'll be a lot different of course, when she's
> here and not home with me. (Cindy, Interview 2)

> It's gets in the way of getting things done. I'm just stock with it 24/7 essentially.
> If we go somewhere, I need to do something I'm on the clock and I'm like let me
> go home and pump. (Patty, Interview 3)

Kangaroo care presented as an opportunity for connection. As their infants

became more stable physiologically, the infants were removed from their incubators and

placed on their mother's chest for kangaroo care. The basic premise of kangaroo care

entails the following: (1) skin to skin contact; (2) exclusive breast feeding; (3) preserving

contact between mother and infant by supporting the dyad's physical, emotional and

psychological needs so that the dyad may remain together (Hamelin & Ramachandran,

1993). All of the participants recognized kangaroo care as one of the first experiences

they remembered in which they felt they were bonding with their baby. Once the infants

were placed on their mother's chest, the participants did not need instruction, but rather

quiet time to get to know their infant's rhythms. Some of the participants felt as though

they were getting to know their baby, and able to alleviate their infant's discomfort.

Kangaroo care was perceived by the participants as a "step to normality"

(Flacking, Ewald, Hedberg, Nyqvist, & Starrin, 2006).

> Any time I really get to be hands on her, I feel better. When I was able to kangaroo her back in the day. Now she's so big, I don't know if she could still fit in my shirt. So when it's just us two. Doing normal little things that I would do outside of here…it helps that I can actually see that he's comfortable with me because that was my main thing like am I hurting him. (Cindy, Interview 3)

But, providing kangaroo care within the NICU presented challenges as well. For Kara,

the lack of privacy as well as the infant's fragile health seemed to undermine her ability

to feel present emotionally.

> She's, like, closer to home or whatever. I think she feels better when I hold her. It's just kind of difficult with all the tubes and the wires and everything and trying to make sure nothing gets pulled out or make sure she's warm, and it's just sometimes hard and I'm just watching her vital screen and it kind of throws me off. I'm like, "Am I doing something wrong? Is she okay? Is she comfortable?"

Additionally, for infants who were particularly ill, the NICU did not allow infants to

engage in kangaroo care until they were more stable physiologically. Since Grace's son

was born at 22 weeks, she was filled with longing for this experience for almost two

months. However, once Grace was able to begin skin-to-skin care she noticed the

frequency of kangaroo care as well as the length of the care positively affected her

familiarity with her son as well as her sense of being a mother. For Grace it seemed that

kangaroo care allowed her to strengthen her relationship with her son at her own pace.

These experiences are also supported by the research on kangaroo care, which has

proposed that skin-to-skin contact may attenuate the negative effects of maternal

separation on the mother-child relationship, both in terms of caregiving sensitivity and as

"micro-regulatory patterns of gaze, affect, and touch" (Feldman et al., 2003, p. 95).

Touch is a particularly important aspect of supporting co-regulation between mother and

infant. In their study using the still-face paradigm with 5-month-old infants, researchers

found that when mothers touched their infants during this interaction, infants' attention

and affect remained unchanged; the control group infants did not receive touch when

mothers became still-faced and they exhibited withdrawn affect (Stack & Muir, 1992).

Summary. As the infants continued to mature, the participants became more

comfortable with such forms of caregiving as taking the babies' temperature, changing

diapers, and holding the syringe while they received tube feedings. All of these

experiences eventually contributed to the participants feeling more comfortable with

caregiving, more familiar with their infants' needs, and more able to assume the role of a

mother. Gaining ownership of the baby through caregiving has been echoed in other

studies as well (Affleck et al., 1991; Heermann et al., 2005) along with feelings of

attachment (Nystrom & Axelsson, 2002). Caregiving helps mothers become active

participants and gain the sense of providing "safe passage" for the infant in the NICU.

For some participants, when their baby was weaned from the ventilator was a big

turning point in the caregiving relationship. Kara felt very anxious about the various

tubes connected to Kiki. She was nervous that she would accidentally pull out a tube and

cause her daughter to go into medical failure. For Kara, less medical equipment meant

less anxiety and as a result, she felt more comfortable caregiving and cuddling. The more

opportunities she had to take care of Kiki, the more her attachment to Kiki deepened and

the more she gained confidence in her own ability to care for Kiki. Kara discussed in her

final interview, the week of Kiki's discharge, how she understands her role as Kiki's

mother now:

> I'm trying to make her as comfortable as I can, even if it makes me be
> uncomfortable; she's coming first regardless of what's happening and going on
> with me. And yeah, just not just plopping her on my chest or whatever. I'm like
> are you comfortable? Is the breathing tube right? Are you okay? Just trying to
> make sure my little baby is okay. Or just checking her, making sure she's clean
> and everything and changing her diaper, making sure it's on right. And the tube
> in the back is not pulling on her neck. (Kara Interview 3, p. 17)

The Protocol-Based Caregiving at Midwest NICU Impeded the Mothers' Ability to

Engage in Caregiving

After examining the individual cases as well as looking for common themes

across cases, a common theme emerged: these five women were struggling to engage in

caregiving. Further consideration of the Midwest NICU as a context revealed that the

culture of treating infants in this NICU was driven by rigid protocol. For example: (1)

inflexible visitation times that did not allow parents access to their infants in the morning

when medical rounds were taking place; (2) caregiving of the infants was not

individualized, but rather was given in a uniform manner to all infants; (3) parents were

on the periphery rather than included as partners in caregiving. For the participants,

protocol-based care seemed to affect the degree and frequency of access parents had to

their infant and the sensitivity of nurses as caregivers.

Access to the infant. Parents expressed frustration over the visitation hours in

the NICU as well as times the infants were scheduled for feedings. The women wanted

to visit their infants at any time of the day or night, but the NICU did not allow visitation

between 9 am to 12 pm because this was when the medical team conducted rounds. This

policy prevented several participants who delivered their infants in the middle of the

night from seeing their infants until much later. Patty reported giving birth in the middle of the night, shortly after birth her son David was taken to the NICU, while she was brought to the maternity ward. Patty recalled:

> They would not let me see him until…this area was closed from 9:30 until 12:00 pm. I was really mad…waiting for my nurse to come in since 6 am, but the shift was switching. She came in 15 minutes to closing time in the NICU. They did bring me here somehow, so I got to see him for 10 minutes. (Interview 1)

Another participant (Grace) felt frustrated because visitation was not possible in the mornings when the medical team conducted their rounds. Grace felt excluded from the decision making process as she was excluded during the time the medical team was developing her son's daily care plan. Grace not only wanted to understand what the team's impression was of her son's progress. She also wanted to have an opportunity to voice her concerns to the team.

Another example related to the infants' feedings, which were scheduled during times that were convenient for the nurses and the medical team rather than according to when the infant was exhibiting signs of hunger. When infants are not fed based on their own hunger cues, they may not be as motivated to eat and thus less likely to be successful at an already difficult task. Mothers also felt that the feedings should take place so that they could have an opportunity to feed their babies.

Sensitivity of nurses as caregivers. Caregiving sensitivity has been defined as the ability to read the infant's cues, to respond promptly, appropriately and contingently especially in times of children's distress, and to cooperate with children's exploratory behaviors (Ainsworth, Blehar & Walter, 1978). When children are cared for sensitively they begin to trust that their caregiver will soothe them and help them to feel safe. As a

result the child begins to have faith in the caregiver's ability to provide a secure base.

Within the context of the NICU, caregiving sensitivity is particularly important given the

ongoing stress of the NICU environment (e.g., physical pain, loud sensory inputs, lack of

proximity to caregiver) as it helps to facilitate infant emotional co-regulation. Caregiving

sensitivity may also serve to buffer against the development of dysregulated stress

responses and social-emotional deficits in premature infants and attenuate feelings of

helplessness, depression, and anxiety in mothers (Hane, Myers, Hofer, & Ludwig, 2015).

Within the Midwest NICU, caregiving lacked sensitivity because it was not

individualized to the infant and thus not consistently contingent to the infant's needs.

The participants reported that the nurses were kind and supportive to them as they

attempted to learn how to care for their infants; the general approach to caring for infants

focused on providing medical care efficiently and effectively. However, caregiving that

is protocol-driven rather than infant-centered may lack individualized supports for the

infants and their mothers. For example, all of the infants were positioned in the same

way in their beds, and the blankets and other materials used to nest each infant were

applied in the same way for each infant, rather than specific to the infants' own needs.

Individualized supports also were not given to infants during heal sticks, diaper changes,

or other transitions. Caregiving duties were not modified to support the infant's efforts to

regulate himself physiologically (e.g., respiratory rate, heart rate) or to support the

infant's ability to soothe himself (e.g., bringing hands to midline, tucking feet, sucking on

fingers). In short, because the nurses did not appear to observe and learn about the

infant's unique needs and preferences, they were unable to respond contingently to the

infant during caregiving and were less able to teach parents how to respond to their own

infant's needs.

      How mothers were taught to care for their infants. The mothers relied heavily

on nurses to teach them how to support their infants. All of the mothers needed help in

understanding how to modify their interactions to assist a medically fragile infant. For

example, they were surprised that they could not touch their infant and talk to their infant

in the way they liked. Nurses helped the women understand how to manipulate the

medical equipment during caregiving tasks such as lifting the infant out of the incubator,

and managing the infant's various tubes during diaper changes and kangaroo care. They

also taught mothers how to hold their baby during tube feedings, how to swaddle, change

diapers, bathe the infant, and how to start feeding the infant via breast or bottle. But, the

guidance that parents received from nurses did not focus on empowering them in learning

how to ease their infants' discomfort, how to observe the infant and read the infants'

behavior in order to inform caregiving practices, and how to determine the most effective

way to minimize the infants' experience of pain and stress during caregiving.

Table 13. Themes Across Cases

Themes	Quotes
Traumatic labor and delivery	Oh my god. It was the most terrifying time ever. I'm not sure. I didn't have time to prepare for it. I never got to take any classes to get ready for anything. I was hoping it would be not as stressful as it was, that it would've been more planned, I guess, not doctors coming in the room suddenly and telling me, "You're in labor. You should probably call somebody and let somebody know." (Patty, Interview 1). Grace was at a barbeque on the fourth of July, she was only 22 weeks pregnant, when she began to experience significant abdominal cramping. 48 hours later she gave birth to an infant that was on the threshold of viability, the medical team could not even make an effort to resuscitate the baby (Grace, Interview 1) I know that's in the back of my mind I was hoping still though that something could be done. But he was going to come. So they had the team come in for him,

	all of his doctors and what they wanted me to do first was push out the water bag because it hadn't broken or anything. So that was horrible. It was like – my mom counted, there were at least 16 people in the room. And I'm like that's the least of my worries right now. It was just crazy (Grace, Interview 1). I had the baby on my bedroom floor, 20 year old sister delivered the baby (Lindsay, Interview 1) Yeah, my sister was upstairs in her room. My sister delivered him, it was like 4:30 in the morning when my water broke, and then I had him 15 minutes after that. I was scared, but I was staying calm because my sister was bawling her eyes out. She was like freaking out, so I had to stay calm (Lindsay, Interview 1). I was just scared. I was really scared, because I'm like, "What if something goes wrong?" It was just so much… I was so anxious, and then, because like I said, I had heart problems.
Delay seeing baby	They would not let me see him until pretty much (until the next morning)—this area is closed from 9:30am until12:00. I was waiting for my nurse to come in, but the shift was switching. She came in 15 minutes to closing time here. She said, "You can't go until you eat something, but if you eat something and you're just throwing up—" It was just a terrible cycle. They did bring me here somehow 10 minutes before 9:30, so I got to see him for 10 minutes. That was pretty hard to see him the first time I was really mad I didn't get to see him earlier too. I was waiting for my nurse to come in since 6:00 in the morning. (Patty, Interview 1). Grace gave birth in the morning, she was able to see Aiden in the nursery a few hour later Cindy saw baby briefly after her c-section Yeah that took forever felt like. But then I still had to go back in ICU and I was still on –I'm trying to remember, I might of still been on magnesium, I can't remember. I felt like I was on that for a while so I couldn't move. I couldn't like get up and use the bathroom, I couldn't do anything, I just had to lay there until the 24 hours was up. So then I was stuck in bed and still couldn't see her. So that was just like a fresh new experience because I was stuck there. I wasn't able to see her until like half way through the next day because I was on the magnesium until 7:00 or 9:00 on Saturday morning. And so it was just frustrating because I wanted to see her again (Cindy, Interview 1). It was kinda stressful because I didn't know what was going on with him. When he came out I just threw a blanket over him with a towel, and my sister went to go unlock the door. But I really didn't see him until he was leaving (Lindsay, Interview 1). Lindsay only saw Bryce the next day, once he was taken to the local hospital to get stabilized and then transferred to XYZ NICU. So everybody (all of her family) went up there and then after that they left. The only person who came back to my room was him, and then we went to sleep and then I woke up the next morning, he took me up there to see her. I didn't get to see her until the next day (Kara, Interview 1).
Feel cheated	I'm still feeling not ready. I feel a little cheated. I wasn't ready to have him outside of me (Patty, Interview 1) I just had tunnel vision. Where is my child? Because I hadn't seen him as of yet.

	I think I probably was feeling cheated, everybody else got to see him except for me (Grace, Interview 1)
	Yeah, you expect to hold your baby and all that, but it wasn't – like I missed that (Cindy, Interview 1)
	I barely, you know, got to live with that and then I found out I was dilated (Kara, Interview 1)
Shock seeing baby	I was so exhausted, I didn't know what to think (Patty, Interview 1)
	He was so tiny and precious. I'm like oh my god. This is him. He's here. That's all I could keep saying. As I mentioned, everything just went so quickly. It was like I – I never really cried. I was just in shock by everything. It didn't really hit me until when I was actually discharged from the hospital and I had to leave without my baby (Grace, interview 1).
	I think I was captivated – right, it wasn't just that he didn't look like a regular baby or anything. I'm looking at him trying to see who he does look like. He has these thick eyebrows. (Grace, Interview 1)
	I didn't think he was mine. It took me a while (Lindsay, Interview 1)
	I was just really scared, like, "Something's going to be wrong," like she wasn't entirely finished developing or something or had like a deformity. I was really scared (Kara, Interview 1).
Baby not human	"She looked like a chicken" (Kara, Interview 3)
	Didn't have time to think about it. I was hoping it would just stay alive, because of how early it was, I was kinda scared that he wasn't going to (Lindsay, Interview 1)
	I know at the beginning it was really hard because you couldn't talk to him and he was just kind of laying there – touch him much because he's little system's not developed yet, so we're not supposed to mess around with it too much. It's like a little glass bowl. My last name's on there, so I guess he's mine right? (Patty, Interview 3)
Leaving baby behind: when mom gets d/c	I did not get much contact until they kicked me out of the hospital, essentially. It was a Sunday. I came to say goodbye, and I just started bawling (Patty, Interview 1)
	I really wanted to cry [inaudible] get to me. And I guess I was still in shock, running off adrenalin and just off of everything that happened, so my mom's like you ready to go? they did let me stay an extra day, but I could be asking to stay all week, though, so…(Grace, Interview 1)
Afraid to hurt the baby	He can't even cry, so it's really intense. You never really know what's the right move especially since he's so tiny and critical as well. So that's – like I said, it's my fear that I'm going to do something that I'm not supposed to do (Grace, Interview 1).
	Well, like when she was born, I was really, really scared. And I think that's when she was under the lights because her skin was jaundice. And then they had her

	humidity in there at like 100 percent. So it was always foggy. And so it's just like – they were like be careful (Kara, Interview 3) I was scared I was gonna break him…He is so teeny. I was freaking out, I didn't want to break his leg or something. (Lindsay, Interview 1)
Feeling helpless	I think I'm still helpless in a way because I really don't know necessarily what to do for him (Grace, Interview 1) When what it was like seeing her baby for the first time, Lindsay responded, "I felt helpless because I couldn't help him" (Lindsay, Interview 1) They're so tiny and just helpless and yes, it's not a good feeling being up here (Kara, Interview 1) Kind of have to watch him in a glass box, and see everybody else take care of him because they know better. Here I'm sitting clueless kind of observing and not knowing anything. I don't get to take him home and he's not really – anybody it feels like not a little person (Patty, Interview 3).
Building a relationship through caregiving	I think I'm personally scared that I might harm him or anything like that, but I can say the nurses, they have been helpful. They asked me if I wanted to bathe him yesterday and just help out a little bit. So I'm like okay, this something that I can at least start doing with him (Grace, Interview 1) Any time I really get to be hands on. Like when I got to give her a bath, breastfeeding. When I was able to kangaroo her back in the day. Now she's so big, I don't know if she could still fit in my shirt. So when it's just us two. Doing normal little things that I would do outside of here…it helps that I can actually see that he's comfortable with me because that was my main thing like am I hurting him (Cindy, Interview 3). I feel a lot more comfortable as he's more stable now. Before like I said in the beginning he was on the ventilator, so tiny, I was very nervous to even touch him. They don't want you to caress him or anything but just hold your hand on him firmly. And to be honest my biggest fear was always was like little small babies – newborn babies even like I went through them six months if I could just pick him up. So this was really out of my comfort zone, and as he steadily progressed, he got bigger, and just able to tolerate more things. I felt more comfortable to hold him. (Grace, Interview 3) Caregiving built the relationship for Cindy: Any time I really get to be hands on. Like when I got to give her a bath, breastfeeding. When I was able to kangaroo her back in the day. Now she's so big, I don't know if she could still fit in my shirt. So when it's just us two. Doing normal little things that I would do outside of here (Cindy, Interview 3). It's something new. I was scared to change her diaper because she's so tiny and I don't want to hurt her. I'm just a little scared and like when I first held her I was really, really scared. I don't want to break her or hurt her. I'm getting a little bit more used to it now (Kara, Interview 3).
Role of nurses in facilitating caregiving	I would say maybe just his primary nurses that he's had even when I was scared to do things; they just kind of throw you out there. I'm like what come on help me do this, and so the more that I interacted with him the more I became comfortable

	with doing (Grace, Interview 3).
	For Patty, the caregiving she received from nurses was very impactful for someone with little social support: I was stuck in the ICU for a week; they would just come in to each lunch with me or breakfast with me because I was there alone a lot of times. So these are the nurses that actually made me survive there. They wouldn't allow me to leave the bed for anything. I had to pee and everything laying down. And that was terrible, and I couldn't get up to shower. And I was stuck in bed for that time. The nurses were wonderful people and they would come in and offer to brush my hair and just hang out with me for a little bit and definitely make a huge difference. I probably would have lost my mind if it wasn't for them (Patty, Interview 3). They're wonderful people. They're teaching me everything, showing me what to do, everything, making it more comfortable [inaudible] which is kinda necessary, since he's going home soon. At least one nurse that sat with me and told me all the little ends and outs of the tricks that she's known and she's used since she was a mom, and now she's a grandma. So she told me all those little things – if this happens you can do this and this happens and you can do this. And if I needed help with burping him she'd help me and tell me which position to put him in. (Patty, Interview 3) The nurses, they're really nice and they're really helpful. They make it a little better. You know, just let me know a lot of things are normal for like preemies or for newborns and things, they're really helpful and informative and they answer questions and give a lot of information. They are really helpful, the nurses (Kara, Interview 3).
Role of pumping breastmilk as caregiving	Cindy felt that pumping breast milk was one of the few things she could do for her daughter while she is in the NICU, and she wanted to do this job well. She wanted to produce enough milk so that Chloe would not need to receive any formula as supplements (Cindy, Interview 1, p.26). After I was discharged from the hospital, I received a pamphlet about prematurity. It talked about how though you may feel helpless, the one thing you can do is provide the baby with your milk. So really it was no question if I was going to pump or anything then because I had to – this is the only thing can physically really even do for him. So yes. (Grace, Interview 1) Yeah, it is. It's like, oh, it's time to go pump again. I'm just dreading it. I fee bad, but you know, you have to do it, so you do it anyway. So it's not necessarily something I look forward to doing. But I think it'll be a lot different of course, when she's there (Cindy, Interview 2). It's gets in the way of getting things done. I'm just stock with it 24/7 essentially. If we go somewhere, I need to do something I'm on the clock and I'm like let me go home and pump (Patty, Interview 3).

15**Summary**

These findings demonstrate that these participants experienced premature birth as traumatic and the NICU environment as intimidating and unfamiliar. Just as in other studies that have examined the impact of the NICU on parents, these participants also reported feeling anxious, fearful, and helpless (Affonso et al., 1992; Redshaw & Harris, 1995; Wereszezak, Miles, & Holditch-Davis, 1997). From other studies we understand that these feelings may negatively affect the nature of the interaction parents have with their infants. The interaction may be further exacerbated by the infant's lower levels of arousal and more subtle attempts at communication (Als, Duffy, & McAnulty, 1988; Eckerman, Oehler, Medvin, & Hannan, 1994; Stjernqvist & Svenningsen, 1990).

Despite being fearful of hurting their infants, the participants eventually became comfortable with performing caregiving routines. At first the participants required a lot of encouragement and support from the nurses to begin caring for their infants' basic needs. Parents learned how to touch their infants, maneuver the infant's medical equipment, and provide basic care. The nurses were instrumental in assisting the participants in taking this next step. Caregiving comprised a range of activities: pumping breast milk, kangaroo care, diaper changes, baths, and feeding. All of the participants described caregiving as a means of normalizing what happened, and as an opportunity to learn about their baby and to confront their own fears.   For the mothers in this study, caregiving appeared to provide relief from alterations in parental role expectations, disruption in meaning systems, and a sense of helplessness. However, the participants struggled to read and interpret their individual infant's needs during certain caregiving tasks, namely feeding.

The Midwest NICUs protocol-based culture did not support family-friendly policies; this appeared to limit opportunities for physical closeness between mothers and their infants. Further, the lack of individualized caregiving limited opportunities for parents to learn about their infant's specific behavioral communication. The Midwest NICU is not alone as a technologically-based neonatal unit. Although family centered care models are becoming more prevalent, research suggests that many NICUs have found it difficult to transform these principles into practices (Gooding et al., 2011). NICUs around the world demonstrate large differences in family-centered and developmentally supportive practices and policies, differences that are related to each neonatal unit's culture and context (Flacking et al., 2012). NICU culture is the summation and functional expression of the values of an organization—its decision-making processes, resource allocations, division and alignment of power, authority, and influence (Baker, King, MacDonald, & Horbar, 2003). Culture, often described as "the way we do our work here" (Ohlinger, Brown, & Laudert, 2003, p. e471), encompasses the beliefs, norms, attitudes, and assumptions that are learned over time, shared by the organization's members, and operate usually at a subconscious level. Just as infants and their mothers in the NICU necessitate an individualized approach to caregiving, neonatal units also are dynamic and have implemented developmental and family centered caregiving with various degrees of success.

Progression of Themes

The three-interview series was conducted for all but one participant (Lindsay). This model of in-depth, phenomenological interviewing involves a series of three separate interviews for each participant. According to Seidman (2006), "people's

behavior becomes meaningful and understandable when placed in the context of their lives and the lives of those around them" (p. 16). The first interview focused more specifically on the pregnancy, labor, and delivery of the infant. Additionally, themes such as seeing the baby for the first time and coming to the NICU were covered. The WMCI was used as the second interview. The WMCI focused on looking forward to imagining what life will be like when the infant is home, thinking about the mother's future life with the infant, as well as describing how she understands the infant and her relationship with her newborn. The third and final interview was conducted during the week of discharge. This interview focused on looking back at the time each family spent in the NICU, and reflecting on what it is like to become a parent of a medically fragile, preterm infant.

In general, themes seemed to progress from shock, fear, and unfamiliarity to gaining more comfort in the NICU, coping with what has happened, and getting to know the baby and identify the baby as their own. Table 12 provides a summary of themes from each of the three interviews.

Table 14. Timeline of Interview Themes

Interview 1	Interview 2	Interview 3
On delivery table no baby	First weeks at home	What's most important?
Guilt, loss	Concerns about future development	Trying to get the baby to eat by mouth in order to get discharged home from NICU
Feeling broken	Making memories	From baby doll to my real baby
Longing to be with baby	Caregiving – build relationship	Gratitude
Afraid to hurt baby	Afraid to hurt baby	Looking back
Pumping as caregiving		Caregiving – role of nurses
Shock		

Findings Based on Research Questions

**Mothers' Internal Working Models of Their Preterm Newborns in the NICU Were
Varied**

Internal working models refer to mental representations of the infant, the mother's

relationship with her infant, and the mother-infant relationship (Bowlby, 1982). These

representations directly impact the mother's subjective experience of being with the

infant (Stern, 1995). Further, the mother's attachment to her own parents in childhood

will guide her ability to sensitively care for her infant (Bowlby, 1982; Stern, 1995;

Zeanah & Benoit, 1995). Although it has been suggested that these internal working

models formed in childhood are stable representations of oneself and one's ability to be

in a relationship with others (Benoit et al., 1997), maternal internal working models are

also shaped by the infant's temperament and biological vulnerability (Slade, 1999). The

NICU context has been identified as a potential risk factor to the parent-child relationship

as this context encompasses preterm birth, separation between mother and infant, and fear

for the child's safety (Bracht, O'Leary, Lee, & O'Brien, 2013; Flacking et al., 2012).

This is the first investigation of maternal internal working models that has taken

place within the NICU. In the present study, the participants' attachment representations

of the relationship with their infants were assessed via the Working Model of the Child

Interview (WMCI) (Zeanah & Benoit, 1995). The WMCI focuses on the mothers'

reaction to her pregnancy, perception of the infant's personality, characterization of her

relationship with her infant, responses to her infant's behavior, and perceived difficulties

in the infant's later development. The participants were also asked to give specific

examples that illustrate the infant's personality and behavior. The participants' narratives

were classified as one of three categories of attachment representation: balanced, distorted, or disengaged. To date, there are only four studies that have used the WMCI to investigate internal working models of mothers with preterm babies (Borghini et al., 2006; Korja, 2009; Meijssen et al., 2011; Tooten et al., 2014). All of the studies were conducted in Scandinavian countries; parents in these countries are fortunate to have generous family leave policies, which enable them to remain present with their infants in the NICU unlike the situation in the U.S.

Findings from these studies have been inconclusive; Korja (2009) and Meijssen et al. (2011) found that their distribution of balanced versus non-balanced attachment representation was similar to distributions found in studies of mothers of healthy, full-term children (Rosenblum, Zeanah, McDonough, & Muzik, 2004; Wood, Hargreaves & Marks, 2004). In contrast, Borghini et al. (2006) noted that a larger percentage of preterm infant dyads had non-balanced representations at 18 months corrected age. Two of these studies also described limitations to generalizability: (1) Borghini et al.'s study did not control for SES; (2) Meijssen et al.'s study was an intervention study that used the WMCI as an outcome variable, and the study did not have a full term control group.

Korja's (2009) study indicated the smallest variation of balanced narratives between full term and preterm cohorts. The following year, Korja et al. (2010) conducted another study examining the relationship between attachment representations (via WMCI) and the quality of mother infant interaction in preterm and full term infants. The quality of interaction was related to the mothers' WMCI classification. Specifically distorted representations were strongly related to negative mother-infant interaction.

Table 15. WMCI Category and Behavioral Observation

Mother	WMCI category	IWM special features	Behavioral observation: feeding	Behavioral observation: diaper
Patty	Distorted	Confused	Insensitive	Sensitive
Cindy	Balanced	Restricted	Insensitive	n/a
Grace	Balanced	Full	n/a	Sensitive
Lindsay	No data	No data	n/a	Sensitive
Kara	Distorted	Confused	Insensitive	n/a

In the present study, four of five subjects participated in the WMCI; results are summarized in Table 10. Half of the participants exhibited two different variations of *balanced* representations: balanced-full and balanced-restricted. The *balanced-full* narrative indicates moderately rich details about the infant and the parent-child relationship. When a representation is categorized as *balanced-restricted,* mothers demonstrate some degree of emotional distance toward the child, however, not as persistently as a *disengaged* narrative. The remaining two participants exhibited *distorted-confused* classifications on the WMCI; their narratives were characterized by confusion about their role in the relationship and who the infant is as a person, as well as an unsuccessful struggle to be close to their infant.

The frequency of *balanced* representations appears consistent with all four of the other studies, while the higher percentage of *distorted* classifications as well as the absence of *disengaged* (non-balanced) ratings in this sample demonstrates a contrast. Although the other studies found lower percentages of *distorted* classifications, when the WMCI qualitative features analysis was conducted, several items that are consistent with

a distorted narrative were found (in those scored as *balanced)* such as lower levels of coherence and acceptance and greater fear for the infant's safety (Korja, 2009; Meijsson et al., 2011; Tooten et al., 2014).

One explanation for the increased prevalence of distorted narratives in this study could relate to the fact that this study took place in the NICU, rather than six to twelve months after discharge. The participants in this study had participated in the WMCI just 3-4 weeks after birth while the other studies were conducted 6-18 months after preterm birth. All of the participants reported feeling traumatized by the preterm birth experience, prolonged separation from their infants, and limitations to their ability to care for their infants. During the time of the interview, parents had limited opportunities for engaging with their infant and holding their infant. In contrast, parents who have already taken their baby home from the NICU had the opportunity for intimate privacy within their role as the infant's primary caregivers. Further, as preterm infants mature and have the opportunity to rest, learn to eat and sleep more regularly, parents may find that their babies become more available for reciprocal interactions (Vandenberg & Hanson, 2013). Parents of more mature infants, who have been discharged from the NICU and are living at home with their parents for 6 to 12 months, may have qualitatively different experiences in terms of their own emotional availability for the relationship, attachment to the infant, and caregiving experience.

Another explanation for the differences in WMCI findings could be that all four studies took place in Scandinavian countries, which have a considerably different NICU context thanks to state-funded family medical leave and maternity leave policies. However, this explanation seems less likely as this would result in an increase of

balanced representations for the Scandinavian studies. In fact, the studies had a similar

percentage of insecure or non-balanced (distorted and disengaged combined) ratings.

The difference was in the type of non-balanced rating that was earned. Therefore, this

does not explain why the present study had a higher percentage of distorted rather than

disengaged ratings.

Table 16. Previous Studies Using WMCI With Preterm Sample

Study	Cohort	Months after birth	N	Country	Balanced	Distorted	Disengaged	Total Non-Balanced
Tooten et al., 2014	1. 32-37 weeks, 1220-4280 grams	6 mo	62	Netherlands	56%	22%	22%	44%
	2. 25-32 wks, 720-1220 grams	6 mo	56	Netherlands	56%	18%	26%	44%
Meijssen et al. 2011	<32 weeks <1500 grams	18 mo	78	Netherlands	70%	15%	15%	30%
Korja 2009	<32 weeks <1500 grams	12 mo	38	Finland	55%	26%	18%	44%
Borghini et al., 2006	1. 26-33 weeks	6 mo	50	Switzerland	19%	37%	43%	80%
	2. 26-33 weeks	18 mo	50	Switzerland	30%	38%	32%	70%

Quality of the Behavioral Interaction Between Mothers and Their Preterm Infants

During Feeding was Characterized by Anxiety and Intrusive Behavior, Regardless

of WMCI Rating

One of the developmental consequences of sensitive and responsive caregiving is

secure attachment (Bowlby, 1988). When infants receive contingent interactions with a

familiar caregiver, they develop self-regulatory capacities (Sameroff & Fiese, 2000)

through controlling their physiological responses (e.g., heart rate, respiratory rate) and behavioral and social/emotional responses (e.g., attention to task, distress) (Hofer, 1994). Providing sensitive and responsive care to a preterm infant, however, requires greater effort on the caregiver's part. For instance, supportive interactions require the caregiver's attention to the infant, specifically the caregiver's ability to focus on the infant's cues. Caregivers also need to have an understanding and recognition of the infant's organized and disorganized behaviors, sensitivity of environmental inputs, and readiness to assist once the infant becomes overwhelmed (Browne & Talmi, 2005). Furthermore, contingent and supportive caregiving has been shown to support preterm infants' neurobehavioral organization, and improve long-term developmental outcomes (Als et al., 2003).

Based on our understanding of the influence of internal working models on parenting behavior, it would seem likely that the participants' internal working models as measured by the WMCI would be closely tied to their behavioral interactions with their infants, particularly in terms of their sensitivity to their infant, and provision of warmth, comfort and protection. However, until now internal working models have not been studied in the context of the NICU. In this study, behavioral observations of mothers diapering their infants supported this association. However, observations of mothers feeding their preterm infants by bottle did not support this expectation.

Mother-infant observations were conducted near the end of the NICU stay. The observations consisted of mothers engaging in such caregiving tasks as diaper changing and feeding. Two participants were observed changing their baby's diaper (Lindsay and Grace), two were observed feeding their baby (Cindy and Kara), and one was observed

conducting both caregiving tasks (Patty). The participants approached caregiving tasks cautiously, but with greater familiarity now that they were close to discharge and had many opportunities to learn about their infant. In general, the participants who fed their infants seemed to demonstrate a greater degree of anxiety, intrusive behavior, and ascribed negative or insensitive attributions to their infant. For example, Patty seemed to follow David's lead during diaper changes by modulating the loudness of her voice and in how she positioned him (i.e., on his side rather than lifting him up by his legs), but she appeared to be less sensitive to David's needs during feeding. Patty interpreted David's refusal to latch back unto the nipple as indicating that he is a "lazy preemie" rather than considering the feeding context and what may be causing David to refuse to nurse efficiently.

The other two participants who were observed feeding their infants, Cindy and Kara, did not recognize that their infants were having trouble managing the excessive stimulation of the task. During the feeding interaction the participants engaged in more intrusive behavior such as opening the infant's mouth to insert the nipple and maneuvering the infant's body without consideration of the infant's needs or capabilities. Eventually, after the participants' repeated attempts to force their infants to take a large volume of formula, the infants would no longer accept the nipple. The mothers did not seem to anticipate the infants shutting down in this way. They missed several cues, which indicated that their infants were having trouble managing the flow rate of the liquid; this could have been an opportunity to remove the nipple from the infant's mouth and allow the baby to stabilize her respiratory rate.

In contrast, the mothers who were observed changing their infant's diaper (Grace, Lindsay, and Patty), exhibited a different intensity of interaction as they spoke softly to their infants and maneuvered their infant's bodies gently in order to complete the task. The timing of the behavior between mother and infant was also more closely matched to the infant; there was sufficient opportunity for the infant to respond and for the mother to notice.

I propose two explanations for this inconsistency between the participants' internal working model of their infant and their behavioral interaction during feeding. One explanation may be that the participants are unable to read or understand their infants' behavior, as preterm infants may not communicate with the same robust behavior as healthy full-term infants. For example, in a healthy, full-term infant, the infants' subsystems (autonomic, state, motor, self-regulation) are already mature, integrated, and synchronized. In contrast, a preterm infant may be unable to manage environmental inputs, and thus exhibit overactive responses to even minimal sensory input. Furthermore, preterm infants' behavioral communication is often weak and disorganized and often overlooked by caregivers (Wyly, Allen, & Wilson, 1995). If parents do not see the infant's communicative attempts they cannot respond to the behavior contingently or sensitively.

Secondly, feeding is a particularly challenging caregiving task. The act of feeding is physiologically very demanding for all infants, as it involves a highly coordinated process characterized by oral preparation in order to obtain the milk, oral transit of the bolus to the pharynx, and pharyngeal transit of the bolus to the esophagus. In order to safely eat by mouth, the infant needs to have a stable respiratory rate and heart rate at

rest. He must be positioned so that he is able to maintain physiological stability and motor organization to comfortably continue the feeding without compromising his airway. He must regulate his heart rate and respiratory rate, successfully latch onto the nipple, strip the nipple of liquid with his oral structures, control the liquid bolus so that it reaches the pharynx and a swallow is triggered, then as the infant swallows, the passage of liquid must be safely transmitted to the esophagus so that the airway is protected from entrance of fluid.

Furthermore, the context of feeding is often filled with emotion, as this is one of the many normative activities of being a parent. Unfortunately, feeding in the NICU is further complicated by a task-oriented culture, which views the volume that a caregiver can get an infant to ingest as a measure of successful caregiving (Cerro, Zeunert, Simmer & Daniels, 2002). Some parents feel anxious about getting their infants to take in the required amount of milk as this affects how quickly their infant will get discharged from the hospital (Swift & Scholten, 2009). Therefore, feeding an infant by mouth as a parent within the context of a protocol-driven NICU can become a particularly overwhelming task for both mothers and their infants.

Preterm Infants' Capacity for Social Interaction was Only one Dimension of the Participants' Understanding of Themselves as Mothers

In the first few weeks after birth most of the infants spent a most of their time sleeping. Depending on their infant's physiological stability, mothers' were initially limited in the amount of caregiving they engaged in. After the birth, and after the infant's first two or three days in the NICU, all of the participants were discharged from the hospital. Naturally, the physical distance between mothers and their babies had an

impact on the frequency and length of time mothers were able to spend visiting their infants, and as a result, in the number of opportunities for social interaction and caregiving.

Further, during the first two weeks of the infant's hospitalization the mothers' experiences of labor and the birth of the child were at the forefront. They were shaken by their birth experiences and in a state of shock over giving birth so unexpectedly and often traumatically. Some of the participants also suffered feelings of guilt; they felt that their bodies failed them or they did something to precipitate preterm labor. One of the participants (Patty) likened the alien-like NICU environment with its own protocol based culture and language as "waterboarding." She stated,

> There's a lot of information to take in, it is just way too much. No human being can physically take in all the directions and all the technical mumbo jumbo that just is poured right over. It's like waterboarding of information. And you want more because you need to know more, but that's just not possible. Even if you write everything down it's just not. With time maybe…. (Interview 2, p. 51)

During the participants' early days in the NICU, engaging in caregiving activities seemed to be most effective in helping the mothers get to know their infants and feel like they could parent their infants in the way they had hoped. Particularly the following forms of caregiving were useful: kangaroo care, participation in routine caregiving activities (e.g., diapering, bathing), and providing their infants with their own breast milk. During this time, while the participants felt most helpless, it was particularly important for them to be able comfort and support their baby. For example, being able to calm their baby when the baby was upset, feel the baby's body relax during kangaroo care, or observe the baby recognize and respond to them. These experiences provided evidence to the participants that they are successfully caring for their infants and that their infants

are responsive to their care. Most of the participants also found comfort in being able to provide their infants with breast milk. Initiating and sustaining milk production took a tremendous amount of effort for all of the participants, but most of them felt rewarded because this was one of the few things only they could provide for their infants.

As the infants matured and once they began to achieve physiological stability, all of the infants made efforts to interact with their mothers. Engagement was typically demonstrated via scanning the mother's face, sustaining eye contact, and maintaining alertness. By the time infants were physically strong enough to sustain eye contact, all of the participants had opportunities to engage in activities that facilitate bonding such as kangaroo care as well as successful caregiving experiences. Therefore, the infant's increased alertness did not specifically change how the participants felt about themselves as mothers but enhanced their relationship in terms of the joy and pride they felt. Also, the infants' alertness increased the infants' behavioral repertoire, so the participants had more ways of communicating with their infants.

How Each Mother's NICU Experience Affected her Understanding of Herself as a Mother and her Representation of her Infant

All of the women described a very difficult experience of becoming mothers; they grieved the loss of their pregnancy, the loss of control, the loss of their own participation in the delivery of their infants, the loss of their hopes for a healthy infant, as well as the loss of intimate moments shared with their newborn after birth. The women were in a state of disbelief because everything seemed to happen so quickly and in a state of shock that their babies were outside of their body as tiny, preterm infants.

One of the participants marveled at her own image in the mirror, she felt as though she had never been pregnant at all because she delivered the baby so early. It is as if she has somehow lost a "rite of passage between being pregnant, with the fetus still inside, and being a mother taking care of one's newborn" (Baum, Weidberg, Osher, & Kohelet, 2012). As a result, it was difficult for the participants to feel like mothers. These experiences are consistent with theories of maternal identity formation during the last trimester of pregnancy (Rubin, 1975) when the woman is in a state of "primary maternal occupation" (Winnicott, 1958, p. 93).

In fact, during pregnancy a dramatic organization begins to take place at all levels: physical, biological, cognitive, and emotional. "From the level of the body to the level of intimate relationships, family relationships and societal relationships to the level of self-definition and identity formation, the woman's sense of herself and her relationships changes dramatically by the time she gives birth" (Cohen & Slade, 2000). When a pregnancy ends early, mothers of preterm infants experience significant physical, emotional, and psychological stressors. In fact, the circumstances surrounding the birth are likely to disrupt the relationship parents had developed during pregnancy (Talmi & Harmon, 2003). These feelings of disconnection were further exacerbated by the fact that most of the women were unable to get out of bed as their own bodies were healing from Caesarian deliveries. All of the women had to wait at least several hours to an entire day before they could see their infant following the delivery and up to two weeks before they could hold their infant.

Following one month of NICU hospitalization all of the participants were asked about their relationship with their infant. Infants were described in strong terms such as

"fighter, feisty, knows what she wants, smart, stubborn." However, each participant

viewed their relationship with their infant differently. Two mothers did not believe a

relationship had formed yet, one woman described the relationship as budding, and two

of the remaining participants used nonspecific descriptors such as "good bond" and

"positive relationship." In the final interview, the participants were asked how their

experience in the NICU has influenced their relationship with their infant. Kara reflected

on the intensity and challenge of this time.

> Yeah, it definitely has because when you have a baby in the hospital it's a harder experience. You don't have that direct day-to-day contact. I feel like we will still be close if she came normally at 40 weeks and went home. But I feel like it brings me closer, like it's going to make me a stronger mother towards her. I know more of her needs and what she likes and how she's going to interact and just everything. I feel like this experience definitely makes you stronger, and it's different because, even his mom was saying, I never had that experience. All my babies came home with me. And a lot of people – that's why I'm saying, people say it's going to be okay, but they'll never know this experience unless they go through it

> And so yeah, I feel like it makes me stronger, and her stronger. We were both going through something that's not typical. Everybody's baby doesn't have to stay in the hospital. So it takes a lot. I don't have a problem with coming up here and seeing her, but it does take a lot to keep going. And it's only December, and it feels like it's been forever. But it's steady going not even thinking about it. Just thinking about I know she's coming home soon, and don't fret on the little stuff. I feel like it definitely has made me stronger. (Kara Interview 3, p. 19)

Grace felt this experience was a test of her faith in God:

> I guess that's kind of how I looked at it knowing that this is a test, you have to keep your faith and know that God's gonna work everything out in the end. So even when things were real bleak and he had a few days here, really I just prayed even harder and made it through. So that's my testimony don't give up. (Grace Interview 3, p. 14)

Several participants felt that this experience will make them a more cautious and attentive

caregiver and parent. For instance, Cindy discussed how she would worry about Chloe

getting a sick:

> I think because we're just way more overprotective in general now. People are protective of babies, but now it's like, I barely want anyone to touch her. It's like her dad or me. I don't know, I'm extra paranoid. So I think that will definitely impact – until she gets a little bit bigger, and then I think I'll be okay. Because even they were saying if she gets sick, then she's going to get admitted. (Cindy Interview 3, p. 16)

Conclusion

In summary, the cross case analysis shows that the participants experienced the following core themes: (1) trauma as the backdrop to the NICU experience; and (2) caregiving opportunities were critical for building the mother's relationship with her newborn as well as her sense of herself as a mother. When the interviews were reviewed chronologically a progression of themes was noted across cases: from shock, fear, and unfamiliarity to gaining more comfort in the NICU, coping with what has happened, and finally getting to know the baby and identify the baby as their own. Based on the research questions, the following information was obtained from the study:

1. One month after delivering a preterm, medically compromised infant, mothers in this study exhibited a higher percentage of distorted classification on the WMCI than what was found in other studies using the WMCI (i.e., mothers of preterm infants six to twelve months after discharge from the NICU).

2. When the participants fed their infants, their behavior was characterized by anxiety and intrusiveness, regardless of their WMCI rating.

3. The infants' increased alertness did not specifically change how the participants felt about themselves as mothers, but rather enhanced their relationship in terms of the joy and pride they felt. Caregiving experiences enabled the mothers to provide their

infants with comfort and contributed greatly to their perception of themselves as good mothers.

The context of prematurity provides a range of experiences that create a suboptimal beginning for the mother-infant relationship: unexpected and traumatic labor and delivery, prolonged separation, and limited opportunities to engage in caregiving. As a result of premature birth, the medically fragile infant demonstrates weaker signals to communicate his needs. The infant is not able to maintain wakefulness, engage in prolonged eye contact with his mother, or interact with his parents like a full-term infant. However, with support, parents have been taught to recognize and interpret their infants' cues, thus improving caregiving sensitivity (Browne & Talmi, 2005; Feldman, Eidelman, & Sirota, 2002). It is, therefore, particularly important that parents have opportunities to learn about their individual infant's communicative signals through support from NICU nurses as well as through hands-on caregiving activities. When parents are able to provide well-timed interactions that are contingent upon infant cues, they help synchronize the infants' physiological responses (e.g., heart rate, breathing rate, and body temperature), behavioral, social and emotional responses (e.g., distress), and nutritional needs (Hofer, 1994). Furthermore, sensitive interactions such as these provide a foundation for a stable parent-child relationship, support development of infant self-regulatory capacities (Sameroff & Fiese, 2000), and promote infant mental health.

CHAPTER VI

DISCUSSION

This was a multiple methodology study that focused on the evolving parent child

relationship within the context of preterm birth and hospitalization in the NICU. This

study was the first study of the internal working model construct within the NICU, and

was the first to consider both the internal and external features of the parent-child

relationship in this context (Stern, 1995). Given the conceptually specific nature of

qualitative research, the findings and conclusions of this study may not be generalizable

to the entire population of mothers who have preterm infants in the NICU. However, this

multiple case study analysis has provided a detailed picture of these participants'

experiences within the context of one particular NICU, and this information provides

insight that is useful for future research, theoretical exploration, and clinical practice.

The discussion section begins by highlighting two findings in the current study which

support findings that are documented in the literature

Confirmation of Previous Findings

Participants' Struggle to Mother

Several studies have highlighted parents' struggle to adapt to the unique context

of parenting in the NICU. Some studies focused on power struggles mothers encountered

with neonatal nurses (Flacking et al., 2005; Hurst, 2001a, 2001b). Mothers reported

feeling they needed to vigilantly watching over their baby's safety, they feared making

too many demands because they may be labeled as a "difficult mother," and they worked

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hard to advocate for their babies (Hurst, 2001a, 2001b). Other studies concentrated on mothers' process of gaining ownership of their baby while in the NICU. For instance, Heerman et al. (2005) described a process by which 15 mothers developed from outsider to engaged parent, while Jackson's (2003) phenomenological study described a similar continuum evolving from alienation to familiarity.

In this study, the individual lived experiences of each of the five women were underscored through three separate phenomenological interviews, along with the observation of the dyad and observation of the NICU context. The individual case studies outline each woman's experience of becoming a mother within the NICU. The participants struggled to: cope with the trauma of preterm birth (Lasiuk et al., 2013), make sense of their experience, and understand how to help their baby, become comfortable caring for their baby, and negotiate life in the NICU. Unlike Hurst's (2001a, 2001b) cohort, these participants did not encounter power struggles in the NICU. Their struggle progressed on a continuum from alienation to familiarity (Jackson et al., 2003) and outsider to engaged parent (Flacking, 2005) as they learned about their infant and how to best support their infant during his NICU stay (e.g., uncomfortable medical procedures, soothing to sleep when noisy, maintaining emotional closeness). The participants' experiences demonstrate challenges to all of the following components of the parent-child relationship as originally outlined by Stern (1995) (see Figure 1 below).

Figure 1. Stern's (1995) Parent child relationship conceptualization

The cases studies support all four levels of the parent-child relationship. The context of prematurity presented the following barriers to the *infants' internal representation*: limited alertness, and fighting to survive. It is difficult to surmise how the infant's internal representations are impacted as their level of alertness was so compromised, especially at the beginning of the NICU stay. The *infants' behavior* was impacted by their prematurity in that their behavioral cues are more subtle than full term, healthy infants and their needs are highly specific to their physiological status. The infants' behavior was often not supported by the Midwest NICU because the nurses did not always recognize individual communicative attempts and therefore did not respond by individualizing caregiving to each infant's needs. The *mothers' behavior* was impacted by both the context of prematurity as well as the lack of support provided by the Midwest NICU. For example, mothers were unable to read their infants behavioral cues as their infants demonstrate more subtle and more difficult to read behavioral communication as a result of prematurity. However, the mothers did not receive support

from the NICU to build their knowledge of how to interpret their infant's specific

behavior. This led to less attuned caregiving interactions.

Mothers also had limited physical contact with their infants as a result of

Midwest's protocol-based caregiving policies, for example, immediate separation from

infant after birth, limits on times mothers were able to visit their infant in the NICU, and

lack of privacy in the NICU which may limit skin to skin contact. The context of

prematurity also imposed such medical equipment as incubators, tubing used to deliver

oxygen to the infant, provide nutrition and connect infants' to monitors. This equipment

imposed a physical barrier as the women were unable to just pick up their infants. The

mother required assistance from the nurses to teach them how to manage the equipment

while picking up the baby. The equipment also imposed a psychological barrier as it was

a constant reminder to the women that their infants were medically fragile and that they

may die. The Midwest NICU provided the women with assistance in this respect. The

nurses explained the function of the equipment to the participants and provided the

women with strategies for coping with the equipment when holding their newborns.

Finally, the *mothers' internal representations* were impacted in many ways by

both the context of prematurity as well as by the protocol-based caregiving context of the

Midwest NICU. For example, the women's understanding of themselves as mothers was

directly related to their perceived success in comforting their baby and knowing how to

care for their baby. This understanding was undermined by the lack of support the

women received in understanding their infant's individual communicative attempts. It

was difficult for the women to identify what their role was in the context of the NICU as

the NICU was such an unfamiliar place and the medical team initially seemed to

understand the infant better than the parents. The participants did not feel that they could

care for their infant or advocate on their infant's behalf, although by discharge all five

women became more comfortable in this area. The experience of trauma also impacted

the women's ability to feel present in the moment with their infant and to have the

psychological space to take in multiple pieces of information about their infants' medical

status. The participants reported feeling shocked, numb, weak, disoriented, and helpless.

The Impact of Protocol-Based Caregiving on the Attachment and Caregiving

Systems

The cross case analysis further highlighted the role of the protocol-based

caregiving model in the NICU and each participant's ability to parent her critically ill

newborn. Several studies have focused on the mismatch between the protocol-based

NICU environment and the preterm infant's limited capacity for external stimulation (Als

et al., 1994; Als et al., 2004). These studies argue that the infant's cerebral cortex is not

yet mature enough to cope with the impact of the protocol-based NICU, particularly, the

intense degree of unsupported sensory stimulation that infants are subjected to during

routine caregiving (Anand, 2000). For example, loud monitors beeping, bright overhead

lights, phones ringing, and painful procedures with limited support for self-soothing can

be overwhelming for an infant who is supposed to still be growing in the womb. As a

result, these studies have described the impact of the protocol-based NICU on the infant's

neurodevelopment. Longitudinal studies have further demonstrated that infants

hospitalized in NICUs that provide protocol-based caregiving are at risk for several

developmental challenges (Als et al., 2004). Other studies have highlighted the benefits

of family-centered interventions to the parent-child relationship in the NICU (Kleberg,

Hellstrom-Westas, & Widstrom, 2007; Kleberg, Westrup, Stjernqvist, & Lagercrantz, 2002).

In this study, components of protocol-based care were observed to impact the parents' access to their infants as well as the caregiving sensitivity of both nurses and parents. Access to the infants was affected via visitation hours and rigid feeding schedules while caregiving sensitivity was affected by the lack of observation of each infant's individual strengths and challenges as well as lack of individualized caregiving. Individualized, developmentally supportive caregiving could have helped the parents feel closer to their infants and possibly improve the mothers' caregiving sensitivity (Kleberg et al., 2007; Kleberg et al., 2002). A developmentally supportive NICU environment supports the parent-infant relationship by helping parents become competent in understanding their infant's capabilities and behaviors, which in turn supports parents as sensitive caregivers (Lawhon, 2002).

Mothers who receive developmentally supportive care perceive their infants and their relationship with their infants differently than mothers whose babies receive conventional care. In their study of mother's perceptions of the Newborn Individualized Developmental Care Assessment Program (NIDCAP), Kleberg and colleagues (2007) found that mothers in the NIDCAP group were more emotionally connected to their infants. Parents ascribed their connection and ability to understand their infants to the support they received from their infants' nurse. Furthermore, the infants were also more available for interaction with their parents as they exhibited longer periods of face to face interactions during caregiving encounters with their parents. Through increased understanding of the infant's behaviors, parents were able to minimize the infant's

experience of stress during caregiving and the infant was able to conserve energy and be more available for interactions with his caregiver.

Various family-centered care initiatives have yielded promising results and have helped to identify family-centered, developmental care practices as a fundamental component of neonatal care. Parents in NICUs with established developmental care programs have been shown to feel more comfortable helping to care for their infant in the NICU (Cooper, Gooding, & Gallagher, 2007). Skin to skin contact, a developmentally supportive method of caregiving, has also been shown to impact maternal sensitivity and bonding positively (Feldman et al., 2002; Ferber & Makhous, 2004; Gayle & Vandenberg, 1998). Midwest NICU did not have an established program of developmental care. Rather, the NICU worked to staff the unit with experienced neonatal nurses and neonatologists who worked hard to take care of the infant's medical condition and to encourage mothers to learn how to engage in specific caregiving tasks in order to increase their success as caregivers once they are discharged from the hospital.

New Findings

Distorted Internal Working Models are More Common in This Sample

Based on previous research of children who were once hospitalized in the NICU, (Borghini et al., 2006; Korja, 2009; Meijssen et al., 2011; Tooten et al., 2014) this study contains a larger percentage of distorted internal working models on the WMCI than expected. At this time it is difficult to determine why this is the case with this particular sample of participants. As mentioned earlier, these previous studies have different contexts. First, the studies were completed in Scandinavian countries with extended family leave policies. Second, the samples were collected 18 months discharge, when the

child was long out of the NICU. The primary difference in findings is the type of insecure attachment rating on the WMCI: disengaged was more common among the Scandinavian studies while distorted was more common with the present sample. It is possible that the distorted WMCI ratings are related to the recency of the preterm birth combined with prolonged separation from the infant as well as the challenges of trying to provide caregiving to a preterm infant within the NICU. Given that other studies have shown an association between PTSD and distorted maternal representations on the WMCI (Schecter et al., 2005), it is reasonable to consider that traumatic preterm birth influences the mother's internal working model of herself and her child within the context of the NICU. It is possible that there is a cultural difference between the Scandinavian cohorts and the participants in the present study; however, no data exists on differences between the attachment styles in Scandinavian vs. American families.

Insensitive Caregiving and Working Models

Based on evidence that links internal working models to behavior, one would expect to find that sensitive caregiving was more associated with balanced rather than non-balanced working models. In the present study, mothers exhibited insensitive caregiving in bottle feedings regardless of what the WMCI endorsed. This finding is unexpected for mothers who received a *balanced* rating on the WMCI. However, it is difficult to generalize from this, as only three participants were observed feeding their infants and only one of these participants had a *balanced* representation. Still, it is important to consider this finding, as all three women were markedly insensitive in the feeding context. One of the women with a *distorted* rating was observed in two

caregiving contexts (e.g., diapering and feeding), she demonstrated more insensitive behaviors in feeding.

As discussed in Chapter V, feeding is a particularly challenging caregiving task for prematurely born infants and their mothers. Given the mismatch between the infants' highly specific needs and subtle communicative attempts in the NICU, along with the participants' limited ability to read their infant's signals and fewer opportunities to engage in caregiving, the dyads in this study were at particular risk for difficulties with feeding interaction. The ability to feed a medically compromised infant safely, so that the infant is able to coordinate sucking, swallowing, and breathing, is dependent upon the caregiver's ability to understand and respond to the infant's behavioral communications. Through these subtle behaviors, the infant signals his many feeding-specific needs (e.g., when the flow of liquid is too fast/slow, the nipple on the bottle is collapsing, when he needs to take a breath but cannot stop sucking).

In the Midwest NICU, feeding was considered a task: the goal was to get the infant to take as much milk as possible, rather than to support the infant in learning a challenging skill. In fact, studies have shown that nurses who exhibit insensitive caregiving when feeding an infant hamper the infant's development of feeding skills (Shaker, 2010; Thoyre, Holditch-Davis, Schwartz, & Melendez, 2012). An infant's communication of stress or disengagement during feeding should prompt the caregiver to examine the source of stress and how best to support the infant. In the Midwest NICU, the nurses were not skilled at reading individual infant behavior, but rather applied general guidelines for preterm infant caregiving to all infants. Therefore, it is not surprising that the nurses had difficulty and that the mothers did not receive the

educational support needed to assist them in being more successful in feeding in this caregiving context.

Feeding is a highly relevant caregiving activity in the NICU and it often dictates when the infant is discharged home. Feeding interventions to support infants and their caregivers have been the subject of study within multiple disciplines: nursing, speech-language pathology, occupational therapy, gastroenterology, and neonatology. Feeding-specific supports have been suggested using different equipment (e.g., changing the flow rate of the nipple, using different bottles, positioning), modifying feeding behavior (e.g., removing the bottle from the infant's mouth periodically, burping, taking breaks), as well as individualizing caregiving based on the infant's communication (e.g., cue-based feeding). It is helpful to consider the role that the overall caregiving context of the NICU may play in feeding interactions between nurses, parents, and infants. For instance the larger cultural context of the NICU may impact the way nurses perceive their roles as feeders (e.g., trying to get the infant to take as much as possible vs. being supportive of the infant's learning process) and the opportunities that are available to parents (e.g., feedings scheduled according to the NICU's needs rather than when the infant is ready to eat or the mother is available to feed the baby).

Implications

Supporting the Parent-Child Relationship Through Caregiving in the NICU

Based on both the individual and cross-case findings, it is clear that these mothers and infants could have benefitted from more support during their infants' hospitalization in the NICU. Support was needed to cope with the unexpected termination of a pregnancy, traumatic preterm delivery, and loss of the experience of birthing a healthy

newborn. Mothers also needed more support to cope with such NICU-specific challenges

to the parent-child relationship as prolonged separation, learning how to read the cues of

their early born infant, and how to engage in caregiving with a fragile, premature baby.

In particular, parents needed to be cared for along with the infant so that they could

perform as normal a parenting role as possible in a highly abnormal context.

The importance of caregiving to the parent-child relationship is not merely a

parent's desire; it is seminal to the attachment relationship:

> Giving care means being available to children…in times of trouble. It means
> being able to recognize when the person needs care, and doing what it takes to
> provide it. Giving care means being loving: being respectful of the truth of
> another, accepting of a range of ways of being, ways of feeling. It involves
> openness, flexibility, and acceptance. The reason that the ability to give care is
> important for intimacy is that giving care contributes to one's partner's being able
> to be intimate. Being a secure attachment figure for another, being a source of
> comfort, allows another person to turn to one in times of trouble, to share needs
> and longings. (Cassidy, 2001, p. 130)

Caregiving is a central component of attachment, a core aspect of mothering, and a

needed behavior particularly when the infant is stressed. Attuned care assists both

mothers and infants in managing stress. In other words, the infant needs the mother to

care for him just as the mother needs to understand her infant and know how to care for

him in times of stress (Flacking et al., 2012). It is through caregiving that the mothers

were able to feel like parents. For the infant, caregiving is the way in which he learns

that his mother will be there for him in difficult times, that he is worthy of care, and that

he is seen as himself. As Erik Erikson (1980) stated trust is born of care. Caregiving is

the behavioral external component of the parent-child relationship which provides

evidence and meaning to how both mother and infant view themselves.

However, in order for mothers to be effective caregivers in this context, they may need additional support. Mothers need to be able to focus on the infant and to feel well mentally. To be emotionally available to their baby, mothers of infants in the NICU who have experienced trauma during preterm delivery and prolonged separation from the infant during his hospitalization may need mental health services and social support to heal. Additionally, mothers require support to provide infants with the care they need. Mothers could benefit from learning how to read the language of preterm newborns, opportunities to get to know their infant, and privacy to allow for intimate interaction such as kangaroo care and breast-feeding.

Studies have shown that parents are most affected by the alteration of parenting role in the NICU rather than the degree of the infant's prematurity or changing health status (Lasiuk et al., 2013; Shaw et al., 2006).   Prolonged physical separation of mothers and their newborns is also believed to contribute to maternal anxiety and depression in the NICU (Miles, Holditch-Davis, & Schwartz, 2007). These findings may help explain why engaging in caregiving enabled the mothers in this study to feel successful as parents and begin to believe that they were able to build a relationship with their infants. Caregiving gave the participants a sense of agency as well as opportunities to construct a narrative of themselves as parents. In order to support mothers more fully in the context of prematurity, the results of this study support the need to: (1) minimize separation between mothers and their newborns; (2) support mothers as caregivers; (3) address the mothers' experience of trauma after preterm birth and during NICU hospitalization.

At present, the developmental caregiving philosophy supports the first two needs. Developmental care practices encourage neonatal and perinatal practitioners to consider

the minimum degree of interference between mothers and their infants while continuing to monitor and support the health status of the dyad. This caregiving paradigm encourages practitioners to consider the mother and infant as the patient and permits mothers and infants to remain together as much as possible after delivery and during NICU hospitalization. Examples include, keeping the baby close to his mother after delivery, and while the physician performing the preliminary examination when his mother holds the infant, encouraging skin-to-skin contact is encouraged as soon as possible in order to support bonding between mother and infant, and infant thermoregulation and physiological stability. Further, NICUs are encouraged to have an open visitation policy so that parents can visit their infants at any time.

However, the developmentally supportive caregiving paradigm does not take into account the mothers' experience of trauma. Adding trauma-informed caregiving to what is already known about developmentally supportive care would assist clinicians in fully individualizing and appreciating care for mothers and their newborns. Within the context of preterm birth, the mother and her infant have experienced a traumatic event. When children experience a traumatic event, they need to have access to a trusted caregiver in order to feel safe again. This is true for preterm infants and their mothers as well.

Longitudinal studies have shown that a large percentage of mothers exhibit symptoms of traumatization up to 18 months after their infants were discharged from the NICU (Affleck et al., 1991; Eriksson & Pehrsson, 2002). Further, if the traumatic event is left unresolved, post-traumatic stress disorder may develop (Fischer & Riedesser, 1998). Therefore, women who have given birth prematurely to a medically fragile infant need both psychological and practical support. In order to process the traumatic event

psychologically they need an opportunity to mentally organize the events associated with the trauma, access coping strategies, and identify areas in need of assistance. In addition, they need support in their role as mother to a preterm, hospitalized newborn. Dyadic support should focus on increasing opportunities for physical contact, getting to know the infant, learning how to read their infant's language, as well as strategies to soothe the infant when he is uncomfortable and opportunities to provide caregiving in this context.

A review of the trauma intervention literature in the NICU yielded one such study (Jotzo & Poets, 2005). The study's trauma-informed intervention was shown to significantly reduce traumatization symptoms after preterm birth. The approach involved general trauma anticipatory measures (Slaikeu, 1990) as well as components that concentrated on premature birth (Meyer, Zeanah, Boukydis, & Lester, 1993). The crisis intervention contained the following components: (1) assisting the mothers in rebuilding their narrative of the traumatic event, helping them to recall the events; (2) relaxation techniques; (3) education about trauma and stress reactions in order allow mothers to view their behavior as typical response to trauma; (4) additional support during emotional outbursts; (5) exploring psychological coping strategies; (6) assistance with identifying personal resources and current social support; (7) exploring possible solutions for concrete problems (i.e., care of older siblings); and (8) scheduling follow up. The components that were geared toward premature birth included: (1) exploring the mother's perception of her infant's condition in order to identify possible avoidance strategies; (2) exploring parent-infant relationship and the parent's role development; (3) targeting reactions to the NICU environment and relationship with staff; and (4) discussing the relationship with the family and spouse. When the intervention group was compared to

the control group, significant differences were noted. For instance, 76% of the control group mothers showed clinically significant symptoms of trauma at discharge, compared to 36% in the intervention group.

While Jutzo's (2005) study highlights the importance of support for mothers who have endured preterm birth, it does not address the prolonged separation mothers and their newborns experience after birth and the continued trauma mothers experience when their newborn infant remains hospitalized in the NICU. Further research needs to be conducted regarding how to best support mothers' experience of trauma in the NICU. Topics to be studied include: the degree of intervention that is most useful, screening measures to identify mothers in most need of individual psychological intervention, and the impact of interventions that target narrative rebuilding such as scrapbooking and journaling. According to the National Interdisciplinary Task Force on Psychosocial Support of Parents in the NICU (Hall et al., 2015), there are no program standards for psychosocial support services in the NICU at this time. NICU staff have little training in the normal emotional responses parents have in the NICU and how to recognize responses that may need further support. The task force is in the process of defining best practice standards in this area.

Conceptualizing the Parent-Child Relationship in a Protocol-Driven NICU

Chapters II and III considered the parent-child relationship as consisting of both internal and external features for both mother and infant. The participants' experiences demonstrate challenges to all of the components of the parent child relationship as originally outlined by Stern (1995) (see Figure 1).

The literature review also discussed the NICU context. Figure 2 reflects the

NIDCAP model of NICU care (Als, 1992). In this model, the infant and his family are at

the center of the caregiving model. Infant care is not based on his needs alone, but rather

based on the needs of his family. The NICU caregiving plan is then organized around the

family's individual needs.
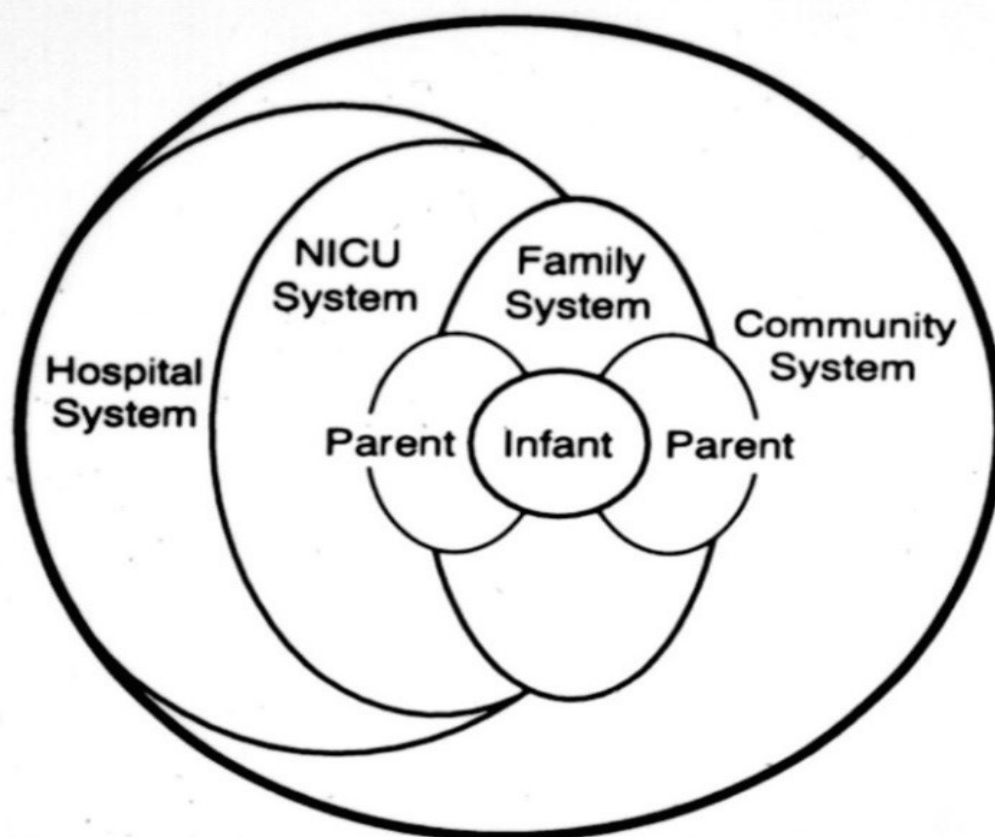
From: Als, H. (1992). Individualized, family-focused developmental care for the very low birthweight preterm infant in the NICU. In S. L. Friedman, & M. D. Sigman (Eds.), *Advances in applied developmental psychology* (Vol. 6, pp. 341-388). Norwood, NJ: Ablex Publishing Company (p. 358).

Figure 2. Model of Developmental Care

Within the Midwest NICU, the parent-infant relationship appeared different from

this model and more closely resembled the model in Figure 3. The caregiving at Midwest

NICU focused on the physiological needs of the baby. The mothers' needs were

considered, but only as they related to the infants' needs (e.g., pumping breastmilk for the baby, task-specific training). In this setting, the mother needed to accommodate to the NICU culture rather than the NICU organizing caregiving around her needs. Mothers were still part of the hospital system as they received follow up care by obstetricians, primary care physicians, and mental health professionals. Other family members (including fathers) were even farther removed from the caregiving process. The lack of focus on fathers and extended family was evidenced in the limited bed-space for the infant and the visitation policies. There was only one chair at the infant's bedside, other family members needed to stand during their visit. The visitation policies only allowed two family members to visit each infant.
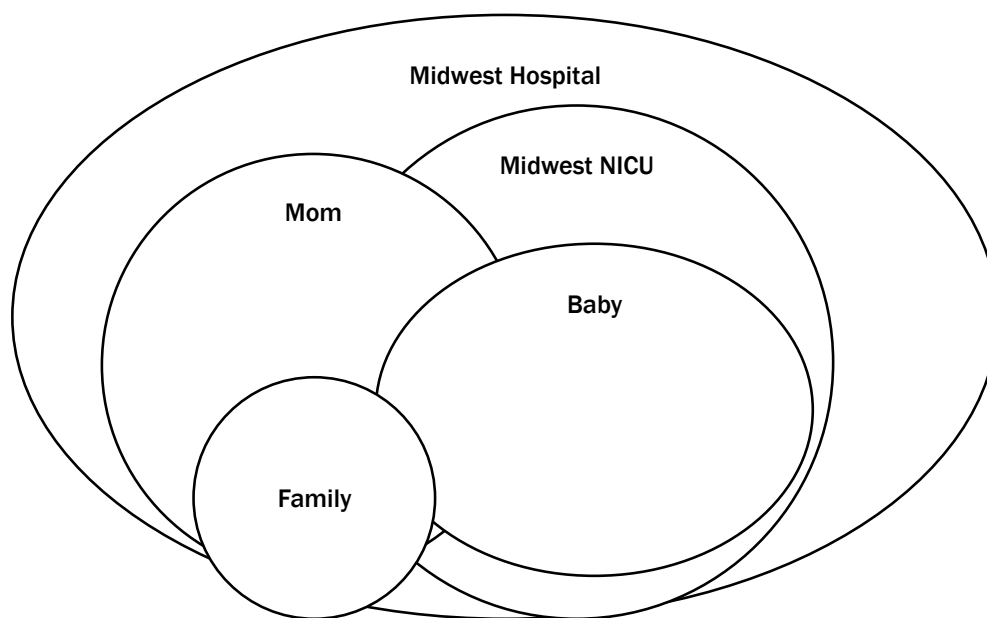
Figure 3. Model of Caregiving at Midwest NICU

Based on the experiences of the five participants and their infants in Midwest NICU, the parent child relationship was challenged on all four levels: infants' internal representation, infants' behavior, mothers' behavior, and mothers' internal representation.

Figure 4 illustrates the ways in which Midwest NICU interfered with the parent-child

relationship. The *infants' internal representation* (internal working model) is being

developed by the consistency and sensitivity of caregiving he or she receives in the

NICU. The infant has a limited level of alertness as he summons his physiological

resources toward survival. The *infants' behavior* is communicative; however, the

communicative signals are less robust than a full term, healthy infant. Further, his

behavior communicates highly specific needs, thus allowing for fewer errors in the

mothers' ability to read the infants' communication and contingent caregiving responses

between the mother and himself. The *mothers' behavior* is not attuned to the infant as

she has difficulty reading the infants' subtle communication and she has limited

knowledge of the specific needs of premature infants (e.g., firm and steady touch, quiet

voices). The mothers' behavior is also impacted by few opportunities to get to know her

infant intimately as there is little privacy in the 40-bed, single room NICU. Further, the

infants' medical equipment (e.g., feeding tubes, ventilator, and incubator) serves as a

physical barrier to mothers as they cannot easily pick up the infant for cuddling, and an

emotional barrier as mothers are reminded of the severity of their infants' illness. The

mothers' internal representation (internal working model) is impacted by the limited

opportunities that are available for caregiving. Caregiving is what built the mothers

internal representation of themselves as good mothers in the NICU, without routine

opportunities for caregiving, mothers struggled to feel like they were good enough as it

seemed that the medical team was more capable of caring for their infants. Further,

infants' in the NICU are subjected to uncomfortable medical equipment, painful medical

procedures, and an overly stimulating NICU environment. Infants in the NICU, like all

infants, have the same attachment needs for security, protection and intimacy. They

signal these needs to their mothers (e.g., crying, squirming, or demonstrating

disorganized breathing), but the mothers are unable to meet their infants' attachment

needs and their own needs to provide caregiving to provide security, protection and

intimacy. Hence, the attachment system is disabled on every level of the relationship.

(IWM) Baby	(Behav) Baby	(Behav) Mom	(IWM) Mom
Limited alertness Surviving Based on caregiving	Subtle communication signals Very specific needs	Not attuned to baby, can't read infant's cues Limited physical contact No privacy Medical equipment physical/ emotional barrier	Caregiving role interrupted Can't protect/ comfort baby Birth trauma: impacts emotional presence
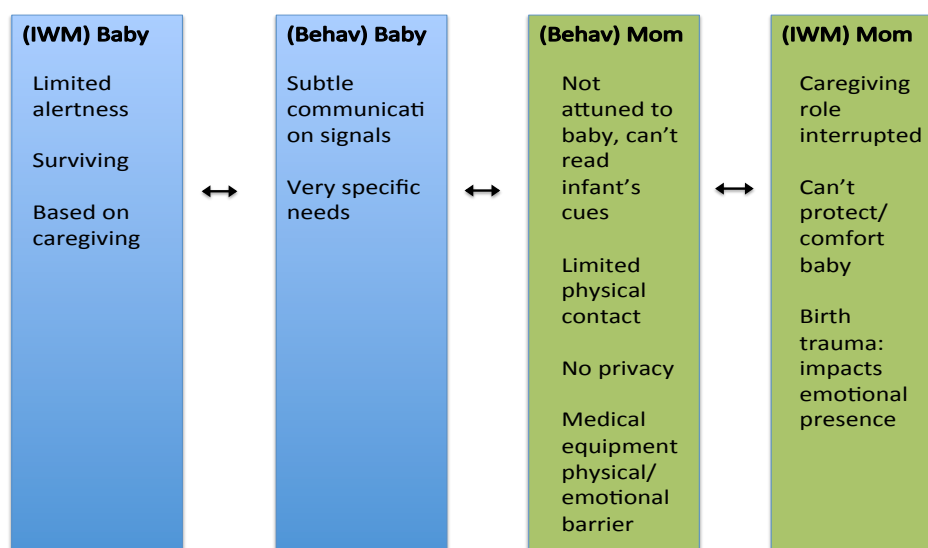
Figure 4. Illustration of the participants' relationships with their newborns within the
Midwest NICU

Strengths and Limitations

The study utilized rigorous methodology via collection of multiple data points,

various types of data, and a combination of qualitative and quantitative instruments. The

data reflected a micro-analytic approach to each of the five cases. The participants were

interviewed multiple times during their infant's hospitalization. Additionally,

observations were conducted of the participants and their babies as well as the NICU environment. Finally, the participants, the infants, and the NICU environment were evaluated using a combination of quantitative and qualitative instrumentation. For example, the participants completed surveys, questionnaires, standardized interviews and phenomenological interviews. The mothers were observed feeding their infants, while the infant's behavior was scored used the NIDCAP neurobehavioral observation framework. The environment was also evaluated via standardized measure as well as informal observation. The participants represented a diverse group of women in terms of race, marital status, and age. The infants also ranged in degree of prematurity as well as severity of medical complications and length of hospitalization in the NICU.

It is important to note that significant limitations were placed on this research given my role as a student involved in my own, independent research. For example, the medical center IRB would not allow any additional interviews (i.e., family members or NICU staff) or administration of a standardized, videotaped behavioral observation of the mothers and their infants. Initially, I had proposed to interview the infants' primary care nurse in order to gain her perspective about the infant, parent-child relationship, as well as her perception of her role as a neonatal nurse with this family. I would also have liked to interview the NICU director in order to understand more clearly what the contributing factors are to maintaining a protocol-driven caregiving philosophy and what his thoughts are on developmentally supportive caregiving. Secondly, I was unable to complete standardized caregiving observations (Parent Child Early Relationship Assessment – PCERA) because the assessment needed to be videotaped, which, according to the IRB, violated patient confidentiality. In fact, obtaining and maintaining IRB approval at both

Loyola University as well as the Midwest medical center was particularly challenging as

the two IRB committees had trouble agreeing with one another. Ultimately, I completed

a multiple case study with some limitations in terms of data that utilized multiple

perspectives.

Finally, the Midwest NICU was not the context I originally intended to study.

The first NICU that I selected was chosen as it presented as the caregiving context within

the NICU presented as a blend of both protocol-based and developmentally supportive

caregiving. Unfortunately, the IRB application at this medical center was denied as I was

not an employee and the NICU was considered a highly vulnerable population. I

hypothesize that there would have been some differences to parent-child relationships in

this context as this NICU had some nurses who were skilled in reading the language of

the infant and supporting parents to understand preterm infant communication. Also, the

unit offers parent support groups in order to assist parents in forming relationships with

other parents in the NICU.

Role of Reflexivity

During the course of this study, I found my previous experience as a pediatric

speech pathologist, feeding specialist, and NICU developmental specialist to be helpful in

coordinating the data collection, establishing rapport, and conducting accurate

assessments of the infant. These skills supported my ability to quickly acclimate to the

NICU environment and gain access to the infants and their family. I understood the ways

in which I needed to communicate with the nurses and doctors in order to schedule

interviews and find a quiet space in which to conduct interviews in the NICU. When

attempting to arrange for meetings with parents, I also understood the importance of

checking in with parents prior to our scheduled meetings, as my study was not at the forefront of their mind. I tried to make meetings with mothers as convenient, comfortable, and accommodating as possible. I worked to adjust to their schedules and made myself available at a moment's notice if needed, scheduling meetings on weekends or evenings if that is what the participant required. I located a quiet, dimly lit room near the NICU. I arrived early, offered snacks, and sat quietly, allowing the women to talk for a while before beginning my interview. After the first interview, most of the participants looked forward to the following meeting and four out of five of the participants were disappointed that the third interview was our last.

Through the repeated phenomenological driven interviews, the Working Model of the Child Interview, and the opportunity to meet with women during this very tender time in their development as mothers, I became keenly aware of their unique struggles and vulnerabilities after giving birth to medically fragile newborns. Throughout the study, I worked hard to connect with each woman's experience in the NICU while continuing to maintain enough psychological distance to be able to process the information they conveyed. At times this became a particularly taxing expectation, as I am a mother of three children myself. One of my children was eight months old at the time I began conducting my first interview. Therefore, the experience of birth was not far from my mind. I was able to relate easily to the participants' hopes and dreams for a healthy infant. Their pain was quite palpable to me as well. At times, I was unable to analyze the data right away; I relied on audio recording and transcription to create psychological distance in order to make sense of each woman's experience.

The transcripts were analyzed one case at a time. Once all three interviews were completed, they were read in order and general themes were identified. The interviews were read again and placed into context of the specific participant. After all of the interviews were completed and analyzed by case, I went back to compare the themes that emerged across cases, while considering the chronological timeline of each of the themes and how they relate between cases.

Directions for Future Research

This study provides a rich source of research on parent-child relationships in the NICU. Further studies should be conducted regarding the most effective ways to address trauma in the NICU context. Mothers clearly need the support of mental health professionals to work through traumatic experience and identify coping strategies. However, there may be other components of support that can be offered to parents in the NICU. For instance, journaling or scrapbooking have been suggested to parents in the NICU. These experiences can provide an opportunity to rebuild the narrative of the birth and influence a woman's subjective experience of trauma after birth and during NICU hospitalization. Further, there needs to be different points of access to psychosocial support as well as different modalities for care delivery (Hall et al., 2015).

Neonatal nurses who do not work in NICUs that operate under a developmental care framework likely do not receive support in learning to read the language of the newborn and thus to provide sensitive caregiving. Investigating ways of providing education and support to nurses working in protocol-based NICUs would be useful. Further, exploring NICU nurses' internal working models of caregiving as well as attachment experiences and how these states of mind relate to their own caregiving

sensitivity with newborns in the NICU would be a helpful extension of the work that has already been completed on parents and on child care providers' relationship histories and caregiving practices. This research may help to further inform our understanding of caregiving within the context of a protocol-driven NICU and may lay the groundwork for determining how to best support nurses in their work.

Conclusion

This was a multiple case study that was conducted in order to describe the parent child relationship within a protocol based NICU through the lens of attachment theory. The relationship was conceptualized using Stern's (1995) model of parent-child relationship assessment, which included: (1) the internal working model of the infant; (2) the infant's behavior; (3) the mother's behavior; and (4) the internal working model of the mother. A multiple case study approach was utilized in order to highlight the complex nature of the NICU context (e.g., highly technical environment, NICU culture, nurses and doctors as caregivers, and the mother-infant dyad) and observe how the context interacts with the developing mother-child relationship.

A review of the literature on parent-child relationships in the NICU highlighted several shortcomings: the studies looked at IWMs of the parent-preterm child relationship long after the child was discharged from the NICU, and the studies that were conducted in the NICU were ethnographic studies that described the mothers experience with developing ownership of her baby in an unfamiliar context. These studies did not focus on the internal and external features of the parent-child relationship in the NICU context. Studying the relationship in this way not only provided a more complete analysis of what

happened within the relationship, but also how aspects of the NICU context may interfered with the relationship.

Cross-case findings from the study uncovered three themes: (1) mothers experienced trauma; (2) the act of caregiving built the relationship; and (3) protocol-based caregiving at Midwest NICU interfered with the mother-infant relationship. The research questions yielded the following findings: (1) a larger percentage of distorted internal working models was found in the present study than in previous studies that used the WMCI with preterm samples (Borghini et al., 2006; Korja, 2009; Meijsen et al., 2011; Tooten et al., 2014); (2) the quality of the behavioral interaction between mothers and their preterm infants during feeding was intrusive, regardless of their WMCI rating; (3) meeting the infant's attachment needs (e.g., successfully providing comfort during distress) in the NICU what contributed to the participant's understanding of themselves as "good enough" mothers.

Ultimately, my hope is that this study contributes a more in-depth means of understanding the parent-child relationship within the context of the NICU and an appreciation for mothers' experience of trauma. In addition, the study demonstrated that infant feeding is a particularly vulnerable caregiving practice in this milieu, and knowledge of the many variables within a NICU may interact with the parent-child relationship and potentially undermine the formation of a secure attachment between mothers and their babies.

APPENDIX A

INTRODUCTION LETTER

Dear parent(s),

My name is Ilona Helin and I am a student at Erikson Institute and Loyola University. I am pursuing a doctoral degree in Child Development with an emphasis in Infancy. For my dissertation, I am doing a research project about how the mother-infant relationship evolves within the context of the Newborn Intensive Care Unit.

I will be interviewing mothers and asking them to share their experiences with me, the information you have to share is very important to me. I would like to meet with you three times individually for about an hour at a location of your choosing. If you would prefer to meet at the hospital, I will make a private room available. Additionally, I would like to observe you feeding your baby, at a time that is convenient for you, <u>if you are uncomfortable with this observation, you may opt out of this part of the study</u>.

If you think you might be interested in sharing your story with me, please call me at 847-864-5161. Upon completion of the interviews and observations, you will be given a $25 gift card to Target stores to thank you for your time. At the end of the study, I would be happy to provide you with a summary of my findings.

Please note that all information, including your and your child's name, will be kept confidential. Your participation in the study is completely voluntary and there is absolutely no penalty if you do not choose to participate.

Thank you so much for your time and consideration.

Sincerely,

Ilona Helin
Doctoral Candidate in Child Development
Erikson Institute – Loyola University
ilonahelin@mac.com
847-864-5161

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

I would like to start by asking you some background information about you and your family. Some of these questions might not apply to you, and we apologize for this, however it is important that we ask every one the same things so please bear with us on this. Please try to be as truthful as possible when answering these questions; the answers you give will be kept confidential.

1. Your Age: _____

2. Highest level of education completed (circle one)
   Under 9 years
   9-12 years
   12 yeas or more

3. Occupation: _____

4. What is your marital status? (Circle one)

   Single/never married

   Separated/Divorced

   In relationship but living apart

   In relationship living together

   Married

5. Spouse / partner's relationship to child:

   Biological parent

   Parent's partner (living together)

6. Father's age _____

7. Father's education level

Under 9 years
9-12 years
12 yeas or more

8. Who else shares your household? What is their relationship to you and your child?

9. Have you, your partner or your child's father ever had problems with drugs and/or alcohol?   If yes, which member of the family has the problem?

YES

NO

DON'T KNOW

APPENDIX C

WORKING MODEL OF THE CHILD INTERVIEW QUESTIONS

Mothers' interview Part 3

Modified Working Model of the Child Interview - WMCI (part 2 of WMCI)

We are interested in how parents think and feel about their young children. This interview is a way for us to ask you about your baby and your relationship to him/her. The interview will take us about an hour to complete.

a) **How do you imagine the first few weeks at home: feeding, sleeping, crying, etc.?**

b) **Tell me about how you imagine your baby's developmental milestones, such as sitting up, crawling, walking, smiling, and talking. What do you think about your baby's intelligence early on? What will it be like?**

c) **Do you think your baby will have a regular routine? What will happen if you don't stay in the routine?**

d) **How will the baby react to separations from you? What will it be like for you and for the baby?**

2a) **Describe your impression of the child's personality now.** Give the subject enough time to respond to this before proceeding to the specific descriptors below.

2b**) Pick five words (adjectives) to describe your child's personality now. After you have told me what they are, I will ask you about each one**. For each one, say, **"What it is you imagine about the baby that makes you say that."** Then, **"Tell an example of a specific event that illustrates what you mean by each word that you chose.** Some subjects will have a hard time coming up with five descriptors. If you feel that they cannot come up with five, then move on. The numbers are less important that the descriptions.

3a) **At this point, whom do you expect your baby to remind you of? In what ways?**

In terms of personality characteristics, to which of his/her parents is your baby most

like? Why?

3b) **Are there any family characteristics on your side you expect to find in your**

baby's personality? What about (other parent's) side?

3c) **Have you decided baby's name? How did you/will you choose?** Find out about

family names, etc.

(4)   What do you expect to be unique, or different, or special about your baby

compared to what you know of other children?

(5)   **What about your baby's behavior do you expect to be most difficult for you**

to handle? After a pause, "**Give an example**."

(a)   How often do you think this might occur? How will you feel? What will you

do?

(b)   Do you think the baby will know you don't like it? Why do you think he/she

will do it?

(c)   What do you imagine will happen to this behavior as your child grows older?

Why do you think so?

(6a) **How would you describe your relationship to your baby now?** Give time to

respond.

(6b) **Pick five words (adjectives) to describe your relationship. For each word,**

describe a particular scene you imagine that illustrates what you mean.

(7a) What do you expect will please you most about your relationship with your

baby? What do you think you will want to change about that?

(7b) How do you feel your relationship with your baby will affect your baby's personality? Give ample time to respond to this.

(7c) **Will your relationship to you baby change at all over time? In what ways? How will you feel about the change?**

(8)   Which parent will your baby be closest to? How will you know? Do you expect that to change (as the child gets older, for instance)? How do you expect it to change?

(9)   Do you expect your baby to get upset often? Give some time to respond before proceeding to specific queries. **What will you do at these times? What will you feel like doing when this happens? What will you feel like at these times?**

(a) What about when he/she becomes emotionally upset? Can you imagine a specific example? Indicate that you want an example by providing a reasonably long time to think of one**. What will you do when that happens? What will you feel like doing? What will you feel like?** If the subject becomes extremely anxious and cannot recall an example, then proceed to part (b).**

(b) What about when he/she gets physically hurt a little bit (e.g., scrapes a knee, bumps his/her head)?

(c) What do you imagine it will be like when the baby is sick? How will you feel? What will you do?

(10)   Do you have a favorite story about the baby? I know it's early… but anything you've told to your family or friends.

(11)   Are there any experiences which your child has had which you feel may be a setback for him/her? Why do you think so?

(12)   Do you expect ever to worry about your child? What will you worry about?

(13)   If your child were to be one particular age, what age would you choose?

Why?

(14)   As you look ahead, what will be the most difficult time in your child's

development? Why do you think so?

(15)   What do you expect your child to be like as an adolescent? What makes you

feel this way? What do you expect to be good and not so good about this period in

your child's life?

(16)   Think for a moment of your child as an adult. What hopes and fears do you

have about that time?

(17)   What has it been like, becoming a parent this way?

(18)   What has your experience been like with the nurses and doctors?

(19)   If you had to give another parent who is about to go through this experience

any advice, what would you suggest?

APPENDIX D

MINI-MASQ

Mini-MASQ Questionnaire

ID# _____   Interview: initial   2-month

Date_____   4-month   6-month

Mini-MASQ

Below is a list of feelings, sensations, problems, and experiences that people sometimes have. Read each item and then fill in the blank with the number that best describes how much you have felt or experienced things this way during the past week, including today. Use this scale when answering::

1	2	3	4	5
not at all	a little bit	moderately	quite a bit	extremely

_____   1. Felt really happy
_____   2. Felt tense or "high strung"
_____   3. Felt depressed
_____   4. Was short of breath
_____   5.   Felt withdrawn from other people
_____   6.   Felt dizzy or lightheaded
_____   7.   Felt hopeless
_____   8.   Hands were cold or sweaty
_____   9.   Felt like I had a lot to look forward to
_____   10. Hands were shaky
_____   11. Felt like nothing was very enjoyable
_____   12. Felt keyed up, "on edge"
_____   13. Felt worthless
_____   14. Had trouble swallowing
_____   15. Felt like I had a lot of interesting things to do
_____   16. Had hot or cold spells
_____   17. Felt like a failure
_____   18. Felt like I was choking
_____   19. Felt really lively, "up"
_____   20. Felt uneasy
_____   21. Felt discouraged
_____   22. Muscles twitched or trembled
_____   23. Felt like I had a lot of energy
_____   24. Was trembling or shaking
_____   25. Felt like I was having a lot of fun
_____   26. Had a very dry mouth

APPENDIX E

NORBECK SOCIAL SUPPORT QUESTIONNAIRE

SOCIAL SUPPORT QUESTIONNAIRE

PLEASE READ ALL DIRECTIONS
ON THIS PAGE BEFORE STARTING

Please list each significant person in your life on the right. Consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate the relationship, as in the following example:

Example:

First Name or Initials	Relationship

1. _____Mary T_____   _____friend_____
2. _____Bob_____   _____brother_____
3. _____M.T._____   _____mother_____
4. _____Sam_____   _____friend_____
5. _____Mrs. R._____   _____neighbor_____
   etc.

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

- spouse or partner
- family members or relatives
- friends
- work or school associates
- neighbors
- health care providers
- counselor or therapist
- minister/priest/rabbi
- other

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life.

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

For each person you listed, please answer the following questions by writing in the number that applies.

0 = not at all
1 = a little
2 = moderately
3 = quite a bit
4 = a great deal

Question 1:

How much does this person make you feel liked or loved?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[EMO1]

Question 2:

How much does this person make you feel respected or admired?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____

[EMO2]

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

Page 2

GO ON TO NEXT PAGE

0 = not at all
1 = a little
2 = moderately
3 = quite a bit
4 = a great deal

Question 3:

How much can you confide in
this person?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____
[EMO3]

Question 4:

How much does this person
agree with or support your
actions or thoughts?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____
[EMO4]

Note: Before use, pages 1-4 should be
cut along the dashed center line to allow
the response lines for Questions 1-6 to
align with the Personal Network list on
page 5.

GO ON TO NEXT PAGE

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0 = not at all
1 = a little
2 = moderately
3 = quite a bit
4 = a great deal

Question 5:

If you needed to borrow $10, a ride to the doctor, or some other immediate help, how much could this person usually help?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
20. _____
21. _____
22. _____
23. _____
24. _____
[AID5]

Question 6:

If you were confined to bed for several weeks, how much could this person help you?

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____
17. _____
18. _____
19. _____
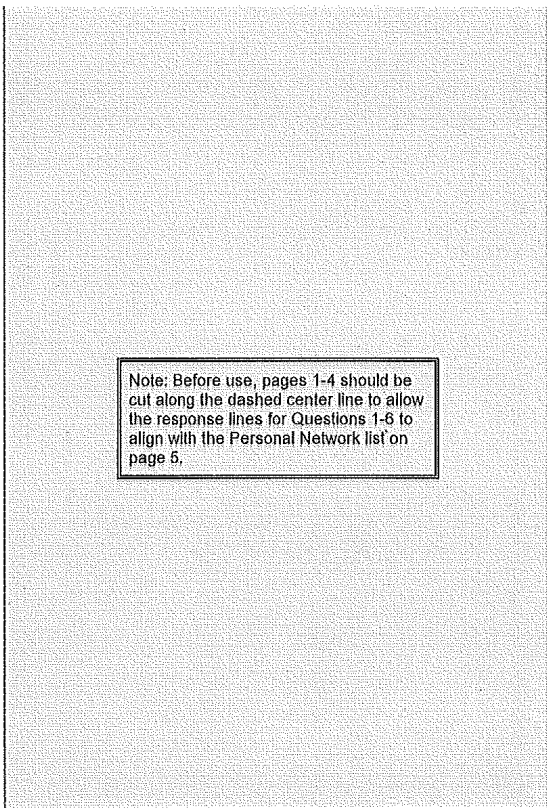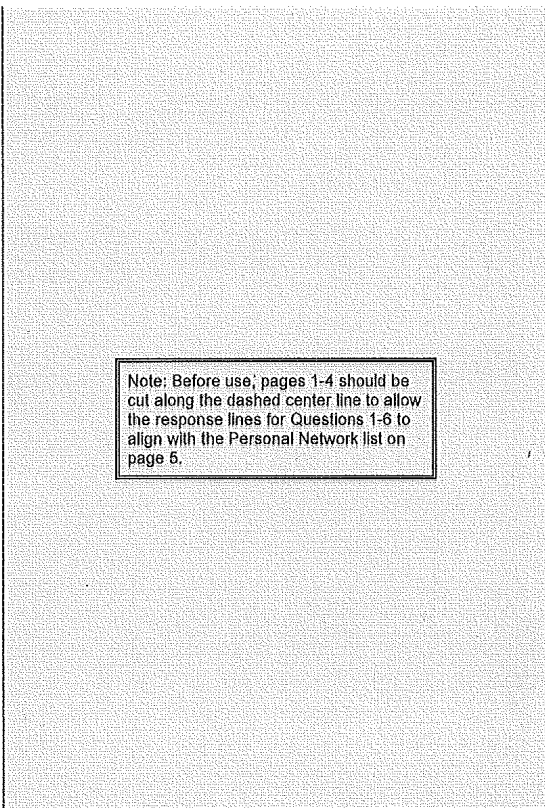20. _____
21. _____
22. _____
23. _____
24. _____
[AID6]

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

GO ON TO NEXT PAGE

Number _____

Date _____

Question 7:

How long have you known this person?

1 = less than 6 months
2 = 6 to 12 months
3 = 1 to 2 years
4 = 2 to 5 years
5 = more than 5 years

Question 8:

How frequently do you usually have contact with this person? (Phone calls, visits, or letters)

5 = daily
4 = weekly
3 = monthly
2 = a few times a year
1 = once a year or less

PERSONAL NETWORK

First Name or Initials   Relationship

Q7	Q8	Name	Relationship	Code
1. _____	1. _____	1. _____	_____	[SOU1]
2. _____	2. _____	2. _____	_____	[SOU2]
3. _____	3. _____	3. _____	_____	[SOU3]
4. _____	4. _____	4. _____	_____	[SOU4]
5. _____	5. _____	5. _____	_____	[SOU5]
6. _____	6. _____	6. _____	_____	[SOU6]
7. _____	7. _____	7. _____	_____	[SOU7]
8. _____	8. _____	8. _____	_____	[SOU8]
9. _____	9. _____	9. _____	_____	[SOU9]
10. _____	10. _____	10. _____	_____	[SOU10]
11. _____	11. _____	11. _____	_____	[SOU11]
12. _____	12. _____	12. _____	_____	[SOU12]
13. _____	13. _____	13. _____	_____	[SOU13]
14. _____	14. _____	14. _____	_____	[SOU14]
15. _____	15. _____	15. _____	_____	[SOU15]
16. _____	16. _____	16. _____	_____	[SOU16]
17. _____	17. _____	17. _____	_____	[SOU17]
18. _____	18. _____	18. _____	_____	[SOU18]
19. _____	19. _____	19. _____	_____	[SOU19]
20. _____	20. _____	20. _____	_____	[SOU20]
21. _____	21. _____	21. _____	_____	[SOU21]
22. _____	22. _____	22. _____	_____	[SOU22]
23. _____	23. _____	23. _____	_____	[SOU23]
24. _____	24. _____	24. _____	_____	[SOU24]
[DURATION]	[FREQCON]			

PLEASE BE SURE YOU HAVE RATED EACH PERSON ON EVERY QUESTION. GO ON TO THE LAST PAGE.

9. During the past year, have you lost any important relationships due to moving, a job change, divorce or separation, death, or some other reason?

       _____ 0. No
       _____ 1. Yes   [LOSS]

IF YOU LOST IMPORTANT RELATIONSHIPS DURING THIS PAST YEAR:

9a. Please indicate <u>the number of persons</u> from each category who are *no longer available* to you.

      _____spouse or partner   [LOSS1]
      _____family members or relatives   [LOSS2]
      _____friends   [LOSS3]
      _____work or school associates   [LOSS4]
      _____neighbors   [LOSS5]
      _____health care providers   [LOSS6]
      _____counselor or therapist   [LOSS7]
      _____minister/priest/rabbi   [LOSS8]
      _____other (specify) _____   [LOSS9]

                                            [LOSSNO]

9b. Overall, how much of your support was provided by these people who are no longer available to you?   [LOSSAMT]
      _____ 0. none at all
      _____ 1. a little
      _____ 2. a moderate amount
      _____ 3. quite a bit
      _____ 4. a great deal

APPENDIX F

NIDCAP CODING INFANT OBSERVATION

Manual for the Naturalistic Observation of Newborn Behavior

Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

Brady ← | HR | → Tachycardia
80 110   160 220

Apnea ← | RR | → Tachypnea
0   40   60 80
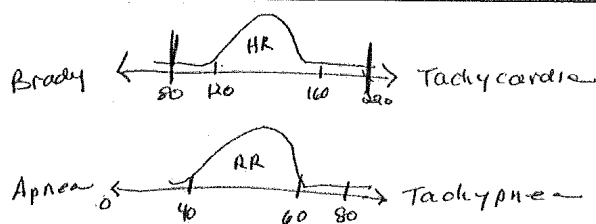
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Much can be learned from systematic, naturalistic observation of an infant in the nursery. A behavioral observation methodology has been developed on the basis of the conceptualizations underlying the APIB (Assessment of Preterm Infants' Behavior).[1] The Behavior Observation Sheet, developed for the recording of information, is designed to be used by an observer who watches the infant in the course of a caregiving interaction. In order to arrive at a sufficient database for the judgment of current thresholds of stability of the autonomic, the motoric, the state organizational, and the self-regulatory systems as discussed in the APIB, it is recommended to observe an infant for up to 20 minutes before the infant is interacted with by a caregiver, then during the course of the caregiving interaction, be it vital signs taking, diaper change, feeding, bathing, blood test, etc., and then for at least 20 minutes after such a caregiving interaction. On average, between 60 and 80 minutes of observation are collected. Such observations, particularly if repeated over time, yield much information regarding the infant's degree of robustness and competence in interacting with the environmental and caregiving inputs provided. They form the basis for caregiving suggestions and modifications in environmental structuring, as outlined and studied elsewhere.[2,3,4,5,6] The approach to caregiving is referred to as Newborn Individualized Developmental Care and Assessment Program (NIDCAP) and the Behavior Observation Sheet is known variously as NIDCAP Observation Sheet, or Naturalistic Observation of Newborn Behavior (NONB) Sheet.

I. Recording of Observation

The materials necessary for a NIDCAP observation, aside from the trained eye of the observer, consist of: 1) the front sheets of the observation package, 2) the observation sheets themselves (1 per 10 minutes, rarely more than 10 sheets for one observation), and 3) the clinical write-up sheets. Also needed are a quiet pen or pencil, a clipboard, and a silent timing device with an easily visible second hand.

Front Sheet
The front sheets are designed for the recording of medical background information usually readily obtained from the infant's medical chart; data on the current status of the infant, again, usually readily obtained from the infant's chart; and a description of the physical environment and circumstances of the observation. Depending on the purpose of the observation, it is helpful to obtain the background information only after an observation in order not to bias the observation. One might react differently to the same behavior, depending on one's knowledge of the history of the infant. After an observation, the observer is encouraged to formulate an estimate of the infant's current age, gestational age at birth, and medical history, and only then check the record. This procedure typically leads more quickly to improved astuteness in the recognition of behavioral patterns associated with specific medical conditions and courses, than does *a priori* available information.

Observation Sheets
Each observation sheet is segmented into 2-minute time intervals and set up in a frequency checklist format for continuous recording of behavior. This method does not permit the accurate documentation of duration of a behavior, only its frequency. If an infant shows an arm extension for 5 seconds, this will be marked with a check in the respective 2-minute time block. The infant who extends an arm for the entire 2-minute epoch will receive the same check mark. Individual

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observers may adapt their own methods of indicating incidental vs. prevalent occurrences within a 2-minute epoch. For statistical data analysis, only the occurrence of the event itself would be available.

It is recommended that observers walk the path from the hospital entrance to the infant's bedside, orient themselves to the infant and the infant's bedspace in relationship to the larger nursery space and the hospital itself, and then record the environmental parameters on the respective form. They then mark in the top left row of the first observation sheet the starting time of the direct behavioral observation, and then mark the five 2-minute intervals across the top of the sheet, indicated in the two sets of 5 columns.

Time: | 10:06 | :08 | :10 | :12 | :14 | | 10:06 | :08 | :10 | :12 | :14 |

In contrast to the behavioral data, which are recorded in continuous fashion, the parametric autonomic data collected are recorded in a time sampling fashion. The sheet is set up for the 2-minute time sampling of heart rate (HR), respiratory rate (RR), and transcutaneous oxygen pressure (TcPO$_2$) or pulse oximetry reading (SaO$_2$). Heart rate and SaO$_2$ (TcPO$_2$) are recorded if the child is monitored for these parameters, in which case the reading, typically displayed digitally, is recorded every 2 minutes. Respiration rate is not recorded off the monitor. Instead, at the onset of a 2-minute interval the observer observes and counts respirations for 30 seconds using the watch or clock at hand and multiplies by 2. It is at this point, 30 seconds into the 2-minute observation period, that HR and SaO$_2$ are read off the respective monitors. The observer continues to watch the child for the remainder of the 1-1/2 minutes until the next 2-minute block starts. In the box preceding the parametric autonomic monitor data, HR, RR, and SaO$_2$ (TcPO$_2$), the current caregiving interactions (manipulation), e.g., feeding, diaper change) is recorded, again for every 2-minute interval.

Recording of occurrence of behavior using this methodology shows good interobserver reliability after-training and practice. Some behaviors and positions do not change frequently, while others are highly variable in their occurrence. Of course, some infants are much more active and variable than others.

II. Definition of Behaviors

The behaviors observed are organized into Autonomic/Visceral, State, Motor, and Attention-Related behavior groups.

A. Autonomic Behaviors

These are subgrouped into respiration patterns, color, autonomic instability-related motor patterns, and visceral and respiratory behaviors.

[handwritten in left margin: consider / Brthg pattern / HR / Color / BM / Digestion / Visceral signs: / gagging etc]*

1. Respiration

Regular:	The breath-to-breath interval is steady.
• Irregular:	The breath-to-breath interval is variable, at times short, at times longer.
• Slow:	Less than at a comparable rate of 40 respirations/minute.
• Fast:	More than at a comparable rate of 60 respirations/minute.
Pause:	Any cessation of respiration for equal to or longer than 2 seconds. A pause longer than 8 seconds is also marked in the state related behavior group as AA.

More than one category may be checked, e.g., regular and slow, or irregular and slow and fast and/or pause.

2. Color

• Jaundice:	Yellowish appearance; yellowness of skin and whites of eyes.
• Pink:	Good perfusion with pink color throughout the face, including mouth and temple area; if trunk and extremities are observable the same criteria apply.
• Pale:	Whitish, sallow appearance in parts of face, e.g., forehead, nose or mouth area, temples or overall skin color appearance. Gray, although one hopes it is not observed, would be noted with a special comment under pale.
• Webbed:	Pattern of surface blood vessels visible in the form of a net or web, often in face, neck, at times total body surface including extremities.
• Red:	Overly perfused, plethoric appearing color.
• Dusky:	Purple, dark hue of face parts of the face, or body surface.
• Blue:	Cyanotic in mouth area or other areas of the face, trunk, or extremities.

More than one color category may be appropriate to mark either because of temporal fluctuations or because patches of various colors are observed (e.g., pale and blue or dusky and webbed, etc.). Notes as to special circumstances such as harlequin pattern should be made.

3. Autonomic Instability-Related Motor Patterns

- Tremor: Trembling or quivering of any part of or of the whole body, e.g., leg tremor, chin tremor.

- Startle: Sudden large amplitude jumping movement of arms or trunk or legs or whole body.

- Twitch: (face, body, extremities) Small amplitude, brief contractile response of a skeletal muscle, elicited presumably by a single maximal volley of impulses in the neurons supplying it; marked as to the location of its occurrence.

4. Visceral and Respiratory Behaviors

- Spit up: Any bringing up of feeding or saliva; more than a drool is required.

- Gag: The infant appears to choke momentarily or gulp; the respiratory pattern is disrupted during a gag. Gags are often but not necessarily accompanied by mild mouth opening.

- Burp: The infant brings up air in an expiratory burst.

- Hiccough: The infant hiccoughs, i.e., makes one or several repetitive sharp inspiratory sounds with spasm of the glottis and diaphragm.

- BM Grunt: Bowel movement grunting or straining. The infant's face and body display the straining often associated with bowel movements and/or the infant emits the grunting sounds often associated with bowel movements and/or actually passes gas or defecates.

- Sounds: The infants emits undifferentiated whimperlike sounds that resemble diffusely disinhibited vocal discharges.

- Sigh: The infant in- and exhales, perhaps audibly, in a breath longer and deeper than the current respiratory pattern observed.

   • Gasp: The infant draws in a respiration sharply or laboriously, often after a respiratory pause; the infant may not apparently complete the inspiration and does not move smoothly to the next expiration.

B. Motor System Behaviors

These are subgrouped into general extremity and trunk behaviors, behaviors of the face, and specific extremity behaviors.

Look @

1. General Extremity and Trunk Behaviors

posture

Muscle tone

Quality of mvmt

   • Flaccid arm(s):   The tone of one or both arms is very low and the arm(s) lie, are held, or move flaccidly or limply. Flexor or extensor postural adjustment or movement is marked respectively.

   • Flaccid leg(s):   The tone of one or both legs is very low and the leg(s) lie, are held, or move flaccidly or limply. Again, flexor or extensor postural adjustment is marked respectively.

Note: It is important to differentiate flaccidity from relaxation. The easiest way to learn to distinguish the two qualities of muscle tone is to test the relative degree of tone by lifting the limb in question. If tone is flaccid a droopy, limp reaction will be felt; if tone is present, a self-maintained tonic response will be felt.

   • Flexed or Tucked Arm(s):

Act:	Activity
Post:	Posture
Activity:	Refers to the current flexor movement or act of tucking in of the arm(s). This may be repetitive activity or one adjustment.
Posture:	Refers to the maintenance of arm(s) in a flexor or tucked position.

   • Flexed or Tucked Leg(s):

Act:	Activity
Post:	Posture
Activity:	Refers to the active flexor movement or act of tucking in of the leg(s), whether it is then maintained or not. It may be repetitive activity or one flexor adjustment.
Posture:	Refers to the maintenance of the leg(s) in a flexor or tucked position.

- Extend Arm(s):

Act:	Activity
Post:	Posture
Activity:	Refers to the active extension movement of one or both arms This may be a single or several consecutive actions, often alternating with some flexor movement, in which case both *extend act* and *flex act* are marked.
Posture:	Refers to the maintenance of arm(s) in extension either in mid air or on a surface.

- Extend Leg(s):

Act:	Activity
Post:	Posture
Activity:	Refers to the active extension movement of one or both legs. This may be a single or several consecutive actions, often alternating with some flexor movement, in which case both *extend act* and *flex act* are marked.
Posture:	Refers to the maintenance of leg(s) in extension either in mid air or on a surface.

- Sm Mvmt Arms: Smooth movement of arms

- Sm Mvmt Legs: Smooth movement of legs

- Sm Mvmt Trunk: Smooth movement of trunk

  Refers to smooth movement of arms, legs, or trunk, balanced in terms of extensor and flexor component, indicating modulated movement control.

- Stretch/Drown: This is a configuration of labored trunkal extension, often also accompanied by arm extension and at times leg extension, which is then followed by an apparent effort to move the trunk back into flexion. This pattern of stretching and tucking may be repeated several times. At times the stretching component is quite prolonged. It frequently follows a pattern of decreasing respiratory rate at times ending in a respiratory pause. Often in the course of this motor pattern, inspiration or expiration has halted, leading to increasing color change to dusky. The pattern gives the impression of the struggling action of drowning, while attempting to regain breathing. It is also referred to as "motor drown." Attention needs to be paid to the successful reactivation of respiration. In successful efforts after a burst of drowning-like behavior, respiration restarts, albeit now often tachypneically. In other cases the drowning may be followed by limpness and a prolonged respiratory pause,

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requiring containment into trunkal and extremity flexion, at times, additional stimulation in order to reactivate breathing.

- Diffuse squirm: Refers to small writhing, wriggling motions of the trunk, often with accompanying movements of the extremities, yet not showing the labored stretching, struggling patterns of stretch/drown. At times, however, diffuse squirm may lead to stretch/drown.

- Arch: Refers to trunkal arching or trunkal extension into an arch and/or head extension, in prone, supine, sidelying or upright position. The upper extremities may or may not extend; the legs often extend.

  Before does \
  Brfr e) stop

- Tuck Trunk: Refers to trunkal tucking or flexion activity, or trunkally maintained flexor posture. The infant curls or tucks trunk and/or shoulders into flexion; often the infant pulls the legs up into flexion or pull the arms in simultaneously. Active trunkal flexion movement in prone, supine, sidelying, or sitting position as well as the maintenance of trunkally flexed posture are marked.

  Dered trunk

- Leg Brace: The infant extends leg(s) and/or feet towards the edge or wall of the incubator, crib, etc., or the caregiver's hand or body, as if in an effort to stabilize, brace, and gain boundary and inhibition to extensor movement or posture. Once touching, the infant may flex the legs and relax while maintaining the bracing, or may restart the active bracing efforts. Even if no surface is available against which the bracing is successful, efforts at apparently seeking such a surface are also marked in this category. The infant may be actively pressing one or both feet against the mattress or a blanket roll, etc.

2. Face Behaviors

- Tongue Extension: The infant's tongue protrudes in extension beyond the lips or extends encased in the lower lip. The behavior is marked whether the infant maintains this tongue posture or engages in repeated extension and flexion or relaxation movements of the tongue. A limply drooping tongue is marked specially. Soft modulated speech-like tongue movements or mouthing are not included in this category.

- Hand on Face: The infant places hand or both hands onto the face or head, or over the ears and maintains this for at least a brief, or for a prolonged period. Hand on Face movement or posture is different from active grasping. It is more protective, appears occluding, and usually involves a soft movement or posture that creates a barrier between the face and the outside world. The hand(s) may be placed palm down or palm up against the face.

- Gape Face: This refers to a drooping open mouth configuration that is the result of decreased lower facial tone. It gives the appearance of exhaustion and facial limpness. It may be paired, however, with eyes open and even environment inspection. It is also seen in active sleep.

- Grimace: This is a facial extension configuration often accompanied by lip retraction and facial retraction and distortion. Eyebrow knitting or frowning is not a part of this configuration, since these represent facial flexion rather than facial extension.

- Smile: Smiling requires facial relaxation without flaccidity and is formed by an at least slightly upward curving of the corner(s) of the mouth, often accompanied by a momentary or prolonged softening of the cheeks.

- Mouthing: The infant makes one or several repetitive lip and/or jaw opening and closing movements. These are distinguished from suck-searching. In mouthing, the lips stay usually soft and relaxed and are not directed forward.

- Suck Search: The infant actively extends the lips forward or sideways and/or opens the mouth in a searching, rooting fashion; the infant often moves the head while doing so, as if seeking something to suck on.

- Sucking: The infant sucks on hand or fingers, on clothing, bedding, the caregiver's finger or mother's breast, a pacifier or other object that the infant has either obtained or that the caregiver has inserted into the infant's mouth.

3. Specific Extremity Movements

- Finger Splay: The infant's hand(s) open and the fingers are extended and separated from each other.

- **Airplane:** The infant's arm(s) are either fully extended out to the side at approximately shoulder level or upper and lower arm are at an angle and are extended out at the shoulder.

- **Salute:** The infant's arm(s) are fully extended into mid air in front of the infant, either singly or simultaneously. This is often but not necessarily accompanied by finger splaying.

- **Sitting on Air:** The infant's legs are extended into mid air either singly or simultaneously. This may occur in supine, side-lying, prone or in upright position.

- **Hand Clasp:** The infant grasps one hand with the other or clutches the hands in midline to the body. Each hand may be closed, yet they hold onto each other or actively press against each other. Interdigitation of fingers of one hand with those of the other hand is a subcategory of hand clasp and is marked here.

- **Foot Clasp:** The infant positions one foot against the other, either foot sole to foot sole or one foot sole against the other ankle or leg, or the infant folds the legs in a crossed position with feet grasping the legs or resting against them.

- **Hand to Mouth:** The infant attempts to bring one or both hands or fingers to the mouth in an apparent effort to suck on them. The effort does not have to be successful to be marked.

- **Grasping:** The infant makes grasping movements with the hands, either directed at the face or body, or in midair, or to the caregiver's hands or fingers or body, the infant's own bottle, tubing or bedding, the side of the incubator or bassinet, etc.

- **Holding On:** The infant is holding on to the examiner's hands or finger or arm, etc.; the infant may have initiated the holding on, or the caregiver may have positioned the infant's hands and the infant then actively holds on.

- **Fisting:** The infant appears to hold on to the own hand by flexing the fingers and forming a fist. Occasionally fisting is observed with an object in the hand (e.g., the edge of a blanket, etc.). The degree of relative tightness of the flexion differentiates the softer holding on from fisting.

C. State-Related Behaviors

These are subgrouped into the states themselves and specific, typically attention-related behaviors. Various configurations of behaviors encompassing eye movements, eye opening and facial expressions, gross body movements, respirations, and tone aspects are used in specific temporal relationships to one another to determine at what level of consciousness an infant is at a particular time. It is possible to make meaningful, systematic distinctions between dynamic transformations of various behavioral configurations which appear to correspond to varying states of availability and conscious responsiveness. The following six levels of observable states are used based on the Brazelton Neonatal Behavioral Assessment Scale (BNBAS).[7] States labeled as A states are the disorganized and diffuse analogues of the states labeled as B states, which are robust, well modulated states. *→ B state* *(handwritten)*

1. Sleep States

Look @: (handwritten)
Range (handwritten)
Robustness (handwritten)
Transition patterns (handwritten)

- State 1   Deep sleep

State 1A: Diffuse deep sleep with obligatory regular breathing or breathing in synchrony with only the respirator, eyes closed, no eye movements under closed lids; quiet facial expression; no spontaneous activity; typically poor color.

State 1B: Robust deep sleep with predominantly modulated regular breathing; eyes closed, no eye movements under closed lids, relaxed facial expression; no spontaneous activity except isolated startles.

- State 2   Light sleep

State 2A: Diffuse light sleep with eyes closed, rapid eye movements may be observed under closed lids; low amplitude activity level with diffuse and disorganized movements; respirations are irregular and there are many sucking and mouthing movements, whimpers; facial, body, and extremity twitchings, much grimacing; the impression of a diffuse state is given. Color is typically poor.

State 2B: Robust light sleep with eyes closed; rapid eye movements may be observed under closed lids; low activity level with movements and dampened startles; movements are likely to be of lower amplitude and more monitored than in State 1; the infant responds to various internal stimuli with dampened startle. Respirations are more regular, mild sucking and mouthing movements may occur off and on; one or two whimpers may be observed, as well as infrequent sighs or smiles.

2. Transitional States

- State 3   Drowsy

  State 3A: Diffusely drowsy, semi-awake or semi-asleep; eyes may be open or closed, eyelids fluttering or blinking very exaggeratedly; if eyes are open, they may have a glassy veiled look; activity level is variable, with or without interspersed, startles from time to time; diffuse movement; fussing and/or much discharge of vocalization, whimpers, facial grimacing, etc.

  State 3B: Robustly drowsy, as above yet with little discharge of vocalization, whimpers, facial grimacing, etc.

3. Awake States

- State 4   Quietly awake and/or alert

  State 4A: Diffusely awake. Two types of diffuse alertness are distinguished, 4AL and 4AH. L or H is marked instead of a check mark

    4AL: Low keyed, lidded, diffuse awakeness; quiet, minimal motor activity, eyes half open or open with glazed, dull, or pained look, giving the impression of little energy; or focused yet strained alertness, appearing to look through, rather than at, an object or the caregiver.

    4AH: Hyperalert; eyes wide open, giving the impression of panic, fear, or overwhelmedness; appearing to be hooked by the stimulus; the infant seems to have difficulty in modulating or breaking the intensity of the fixation to an object or the caregiver, and appears not in a position to turn the gaze away.

  State 4B: Robustly alert with bright shiny eyes, animated facial expression; the infant appears to focus attention on a source of stimulation or a person and appears to process information actively and with modulation; motor activity is at a minimum.

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- State 5   Actively awake and aroused

  State 5A: Diffusely actively aroused; eyes may or may not be open; the infant is clearly awake and aroused, as indicated by motor arousal, tonus, and distressed facial expression, grimacing, or other signs of discomfort. Vocal fussing, if present, may be diffuse or strained.

  State 5B: Robustly actively aroused; eyes may or may not be open; infant is clearly awake and aroused, with considerable, yet well defined, motor activity. The infant may also be clearly fussing without crying robustly.

- State 6   Highly aroused, agitated, upset, and/or crying

  State 6A: Diffusely highly aroused with intense upset, as indicated by intense grimace and cry face, yet cry sound may be very strained, weak, or absent; intensity of upset is very high.

  State 6B: Robustly highly aroused with rhythmic, intense, lusty crying which is robust and vigorous in sound.

- AA State   Removal from the state continuum

  AA: Should the infant move into a prolonged respiratory pause, e.g., beyond 8 seconds, AA should be marked, indicating that the infant has removed him or herself from the state continuum.

More than one state per 2-minute time block may be marked, depending on the fluctuation of states the infant shows. Operationally, typically a 2- to 3-second duration of a behavioral configuration is necessary to be recognized as a distinct state; however, even briefer excursions, especially into states 4 and 6, are recorded reliably.

D. Attention-Related Behaviors

These behaviors appear to be related to attentional states and seem to be signs of poor modulation, such as fussing, sneezing, and yawning, or they appear to be the expression of various levels of attentional availability, such as eye floating, ooh face, etc.

- Fuss: While fussing is often a component of State 5 behavior, this is not necessarily so. At times fussing occurs in State 3 or even in State 2. Fussing is an audible vocal expression of discomfort, uneasiness, unhappiness, upset, and/or disorganization.

- Yawn: The infant opens the mouth widely, usually with a deep inspiration.

- Sneeze: The infant expels air forcibly from the mouth and nose in an explosive, spasmodic action.

- Face open: The infant, either with eyes open or eyes closed, lifts eyebrows up and extends the forehead upwards. This may occur in sleep state or in awake state.

- Eye Floating: The infant's eyes move in floating, apparently disinhibited fashion, often disjugately. This may be in semi-open eye position or with fully open eyes.

- Avert: The infant actively averts the eyes from a social or inanimate target. The infant may momentarily close them.

- Frown: The infant knits the eyebrows or darkens the eyes by contracting the periocular musculature, engaging in a flexion of the upper face.

- Ooh Face: The infant rounds the mouth and purses the lips or extends them forward in an ooh configuration. This may be with eyes open or closed.

- Locking: The infant locks onto an object or point in the environment or on the caregiver, or may be maintaining a steady gaze fastened in one direction. The sound component of an environmental event may appear to contribute to the locking. It is not clear whether the infant processes what is looked at. The action appears almost obligatory and difficult to modify.

- Cooing: The infant emits a soft, pleasurable, modulated cooing sound.

- Speech Movements: The infant's tongue and lips move in soft, rhythmical, speech-like fashion, while the face is typically relaxed and animated, or the gaze is animatedly engaged with the environment or caregiver.

III. Further Specification of Circumstances

The infant's position in the course of an observation is marked as either prone, supine, or side (side lying). Head position is marked as right, left, or middle, defined by the direction of the face. If side lying is marked, the side the infant is lying on is indicated.

OBSERVATION SHEET

Name: _____ Date: _____ Sheet Number: _____

	Time:	0-2	3-4	5-6	7-8	9-10
Resp:	Regular					
	Irregular					
	Slow					
	Fast					
	Pause					
Color:	Jaundice					
	Pink					
	Pale					
	Webb					
	Red					
	Dusky					
	Blue					
	Tremor					
	Startle					
	Twitch Face					
	Twitch Body					
	Twitch Extremities					
Visceral/ Resp:	Spit up					
	Gag					
	Burp					
	Hiccough					
	BM Grunt					
	Sounds					
	Sigh					
	Gasp					
Motor:	Flaccid Arm(s)					
	Flaccid leg(s)					
	Flexed/Tucked Arms Act.					
	Flexed/Tucked Arms Post.					
	Flexed/Tucked Legs Act.					
	Flexed/Tucked Legs Post.					
	Extend Arms Act.					
	Extend Arms Post.					
	Extend Legs Act.					
	Extend Legs Post.					
	Smooth Mvmt Arms					
	Smooth Mvmt Legs					
	Smooth Mvmt Trunk					
	Stretch/Drown					
	Diffuse Squirm					
	Arch					
	Tuck Trunk					
	Leg Brace					
Face:	Tongue Extension					
	Hand on Face					
	Gape Face					
	Grimace					
	Smile					

	Time:	0-2	3-4	5-6	7-8	9-10
State:	1A					
	1B					
	2A					
	2B					
	3A					
	3B					
	4A					
	4B					
	5A					
	5B					
	6A					
	6B					
	AA					
Face (cont.):	Mouthing					
	Suck Search					
	Sucking					
Extrem.:	Finger Splay					
	Airplane					
	Salute					
	Sitting On Air					
	Hand Clasp					
	Foot Clasp					
	Hand to Mouth					
	Grasping					
	Holding On					
	Fisting					
Attention:	Fuss					
	Yawn					
	Sneeze					
	Face Open					
	Eye Floating					
	Avert					
	Frown					
	Ooh Face					
	Locking					
	Cooing					
	Speech Mvmt.					
Posture:	(Prone, Supine, Side)					
Head:	(Right, Left, Middle)					
Location:	(Crib, Incubator, Held)					
Manipulation:						
	Heart Rate					
	Respiration Rate					
	TcPO$_2$/SaO$_2$					

APPENDIX G

NIDCAP CODING ENVIRONMENT

Profile of the Nursery Environment and of Care Components

Template Manual, Part I

Heidelise Als, Deborah Buehler, Deborah Kerr, Emily Feinberg, and *Linda Gilkerson
Children's Hospital, Boston, and *Erikson Institute, Chicago, 1990, 1995, 1997

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Introduction

The following 5-point rating scales have been developed in an effort to document aspects of the physical environment and of the organization of caregiving which infant and family experience in the course of hospitalization. Nursery refers to NICU (newborn intensive care nursery), SCN (special care nursery), and/or other hospital nursery setting respectively.

Aspects of environment and care are measured on 5-point scales; a score of 1 reflects lack of consideration or misunderstanding of developmental opportunities; a score of 5 reflects a high degree of developmental sensitivity. NA (not applicable) is marked when the particular aspect is not available to be observed, or does not apply.

(handwritten margin note: Assessment of environment & care on 5 point scales)

The scales are grouped into the following areas:

A. Physical environment of the nursery
B. Physical environment of the infants' bedspace
C. Specific aspects of direct infant care

Ratings are performed by a trained observer who has achieved reliability in the NIDCAP® (Newborn Individualized Developmental Care and Assessment Program) methodology, and has established reliability with a designated NIDCAP® trainer in the use of the templates. Template scoring is appropriate after a full NIDCAP® observation. The parameters measured are rated as they relate to the specific infant observed and to that infant's family at the particular time point of that observation.

Appropriate uses of the template scales are documentation of change in the course of a nursery's adoption of developmental care as framework of care delivery; documentation of difference in care within nurseries, or across nurseries; examination of the relationship of environmental and caregiving parameters to infant, family, and staff functioning and satisfaction, and others.

The scales have been developed in the context of the National Collaborative Research Institute on Early Childhood Intervention (NCRI-ECI) (1989–1994), entitled "Family-Focused, Individualized Developmental Care for the Very Low Birthweight Infant," funded by the U. S. Department of Education Office of Special Education Programs (OSEP), Early Education Programs for Children with Disabilities (EEPCD). The institute was directed by Dr. Heidelise Als and co-directed by Dr. Linda Gilkerson. The scales were systematically used at all five collaborating sites (4 NICUs and 1 SCN) in the context of weekly NIDCAP® observations of the experimental group infants studied, in order to assess change in the course of the intervention phase. Additionally, they were used every six months in comparison of control and experimental group environments and care. The scales were found to be reliable as well as sensitive to temporal change and to group differences.

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Part II of the Template Manual is currently under revision. It will provide scales yielding a profile of the organizational structures of a nursery. Included will be: I. Staffing aspects as they relate to direct infant care; II. Clinical management aspects; III. Staff composition, staff training, and staff support; IV. Family-related aspects; and V. Transition systems aspects.

Acknowledgments

A. Physical Environment of the Nursery[*]

1. Location in relation to labor and delivery floor and mother's postpartum room

(1) The Nursery is not in proximity to the Labor and Delivery Floor, nor to the mother's postpartum room.

(2) The Nursery is located adjacent to the Labor and Delivery Floor; the mother's postpartum room is in a separate location.

(3) The Nursery, Labor and Delivery Suite and the mother's' postpartum room are in close proximity to each other; yet accessibility of the Nursery for the postpartum mother is not assured.

(4) The Nursery, Labor and Delivery Suite and the mother's postpartum room are in close proximity to each other on the same floor; transport means (wheelchairs; moveable beds) for the postpartum mother are readily available and the mother may reach the infant's' bedside easily at any time.

(5) The Nursery, Labor and Delivery Suite and the mother's postpartum room are in close proximity to each other and on the same floor. Rooming-in facilities within the nursery at the infant's bedside are available for mother and infant.

2. Appearance

(1) The Nursery has a clinical appearance; walls and floors are plain and institutional; windows are bare or have institutional blinds only; fluorescent lighting is prevalent.

(2) The Nursery is clinical in appearance, some attempt is made to make the Nursery appear home-like, yet it is minimal: there may be an occasional picture or wall hanging, there may be a patterned curtain, or an occasional personal item at a bedspace, or a chair with a soft cushion.

(3) The Nursery has a moderately home-like appearance, while some aspects appear clinical: walls may be soft in color; some lighting may be indirect; the hallway leading to the nursery room may have pictures and home-like decor; there may be some individualization of the bedspace, and an occasional home-like chair; overall, the area appears nevertheless quite clinical.

(4) The Nursery has a definite home-like appearance: comfortable chairs are available to the parents; walls may have home-like wallpaper, borders, and pictures; curtains are on the windows; and lighting is indirect; individualization of bedspaces is

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[*] Nursery refers to the observed infant's nursery environment or care room.

[handwritten margin notes: "Carpet or other soft surface... smell sweeping is not appropriate because infections could... are questionable... is probably inappropriate"]

evident; and a reclining bed-chair is available at each bedside; the path to the infant from entrance to bedspace is friendly and welcoming.

(5)　The Nursery has a definite home-like appearance in terms of furniture, color schemes and lighting. Furthermore, floors are carpeted; home-like lamps with dimmer switches provide individualized lighting for each bedspace; attractive plants are appealingly arranged and are well-tended; individualization of bedspace is consistently evident; furniture at the infant's bedspace is comfortable for the parents and professional caregivers' restful caring and nurturing of the infant (reclining, two-parent bed-chair; outgoing telephone line; side table for personal items).

3.　Physical layout

(1)　Space in the Nursery is very crowded. Housekeeping and medical equipment storage areas, secretarial station and staff sitting spaces are part of the same space as the infant's care area; family space at the bedside is essentially absent.

(2)　The location of the infant care area provides some separation of the infant and family from other unit activities; a treatment or triage area may be designated within the Nursery space yet may be without a physical boundary; equipment storage areas appear separate; secretarial station and staff lounges may be only partially separated from the care area and/or doors separating them may remain open; utility and conference rooms may connect directly to the infant care spaces; family space at bedside is minimal.

(3)　The location of the infant's care area from other activities provides considerable separation of infant and family from interference by other unit activities: the staff lounge may be located very close to the infant care area, etc. Family space at the bedside is available yet limited; a door to the hallway may be consistently open.

(4)　There is thorough separation of the infant's care area from other unit activities. Infant and family are undisturbed by other unit activities: family space at the infant's care area is consistently available; there furthermore is a separate parent room available for the family at any time and the Nursery has an adequate number of parent rooms; there is an adequate changing and storage area for the family; equipment is stored away from the infant and the family; treatment or triage rooms, secretarial stations, utility and conference rooms are separate, which affords the infant and family a peaceful environment in the Nursery.

(5)　[Ample/nursery space is available for infant and family free of interference from other unit activities. Complete and comfortable rooming-in facilities are available for the families in the infant's care room.

[handwritten margin note: "this is important for infection control as well."]

4. **Density and size of bedside space**

   (1)   The infant is in very close proximity to other infants. The parent or caregiver cannot easily fit a chair at the bedside.

   (2)   The infant is in very close proximity to the other infants, though it is possible to fit a chair for the parent or caregiver at the bedside; or there is enough space at the infant's bedside yet the infant is one of many infants cared for in one large, undivided room.

   (3)   There is enough bedspace for the infant and caregiver, yet more than six infants are cared for in the same nursery room.

   (4)   The infant's bedspace is one of 4–6 bedspaces in the nursery room; approximately 120 square feet are allotted for each infant and family; each infant clearly has a distinct space.

   (5)   The infant is cared for in a family-like, semi-private or private room setting with only 2–4 cribs in each spacious care area. There is ample space for each individual infant and family.
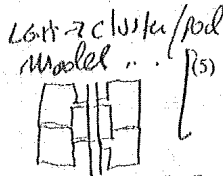
5. **Design of bedside space**

   (1)   Medical equipment appears to consistently interfere with accessibility to the infant; chairs are not consistently available at the bedspace, unused equipment is stored around the bedspace in the room.

   (2)   Medical equipment appears to some extent to interfere with accessibility to the infant; chairs are inconsistently available at the bedspace in the room; some unused equipment may be stored around the bedspaces.

   (3)   Medical equipment sometimes interferes with accessibility to the infant; chairs are available at most of the bedspaces in the room; unused equipment is largely stored away from the bedspaces.

   (4)   Medical equipment is well arranged, providing ready accessibility to the infant; a comfortable chair is available at the infant's bedspace, as well as at each of the other bedspaces; unused equipment is stored away from the bedspaces.

   (5)   Medical equipment is well integrated into the design of the bedspace. The room setting and furniture is family-like and semi-private or private.

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6. **Conduciveness for family participation**

   (1) Space is very limited. The parents of several infants cannot be in the room at the same time nor is there enough room for them to care for their infants.

   (2) Several chairs and/or places for parent-infant interaction are available in the nursery at large, yet not in the infant's care room. A parent room is available for breast feeding and for parent-infant interaction when the infant is well enough.

   (3) Chairs and space are available at the infant's bedspace. The bedspace may be partitioned off within the nursery room. A parent room is available when the infant is well enough.

   (4) A large, comfortable chair that reclines or a bed-chair is available next to the infant's bedspace; more than one parent room is available. Overnight parent rooms are available for the families whose infants are well enough.

   (5) The Nursery room is intimate, supportive, and home-like. A parent bed wide enough for both parents is part of the infant's bedspace. There is enough space and privacy for the parents to sleep , stay overnight, and care in skin-to-skin contact for their infant. A private telephone is installed at the bedspace for the family's personal use; smaller chairs are available for young siblings. There are private over-night rooms with bathroom facilities including showers for parents or families who are living-in with their infants.

7. **Conduciveness for professional care components***

   (1) On-call rooms, laboratories, staff offices, pharmacy, and staff changing rooms, lounges, and conference rooms are in separate and often distant areas of the hospital.

   (2) One or two of the staff areas and/or support service areas are near the nursery space.

   (3) Some of the support services and staff areas are near the nursery space.

   (4) Most of the support services and staff areas are near the nursery space.

   (5) Support services including laboratories and pharmacy, and staff areas including conference rooms, on-call rooms, and staff lounges are near the nursery space.

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* This scale typically cannot be scored on the basis of a direct observation alone.

B. Physical Environment of the Infant's Bedspace

1. **Light level**

(1) The infant is cared for at all times in an environment with bright fluorescent overhead light and/or bright daylight.

(2) During rest periods, the infant is in somewhat muted light; a partial or thin blanket covering may be present over the infant's incubator or bed, or a partial blind is drawn at a window, though the room is generally bright.

(3) For periods, the infant is in semi-darkness; either thick, large blankets cover the entire incubator or crib; the infant's eyes may be shielded during alertness from bright overhead light, or the room is maintained at semi-dark level.

(4) During sleep, the infant is in nearly complete darkness. During alert periods, controlled indirect lighting provides an overall semi-dark environment.

[handwritten margin notes: No specific mention of individual adjustability. These guidelines might be argued... → Is this correct!?]

(5) The infant is in darkness during sleep and there are appropriate levels of light for alertness. Adjustments are titered to the individual infant's developmental progress toward increasing robustness and self-regulation. Individual bedspace lighting with dimmer capacity is used throughout the care room. Lighting is indirect and is controllable by the parent as well as the staff.

2. **Sound level**

(1) Loud human voice and environmental sounds are heard at the infant's bedspace at all times: staff voices, frequent crying sounds from nearby infants, overhead speaker systems, telephone and alarms ringing, sound from the secretarial station, water rushing, doors, equipment and supply sounds, etc.

(2) Loud human voice and environmental sounds are heard at the infant's bedspace much of the time; fluctuations may occur between soft whispering and louder voices; radio, waste receptacles, and sink sounds are clearly heard, as well as sounds from the secretarial station, hallway, etc.

(3) Loud human voice and environmental sounds are heard some of the time; at times human voices are held at soft levels; a radio may be heard at a low level; a sink may be used relatively quietly.

[handwritten margin note: A clear & very effective intervention]

(4) Human voice and environmental sounds are kept to a minimum. Very low levels of sound are present. There appears to be felt stripping on waste receptacles and drawers. Incubator portholes and cupboard doors are closed quietly; equipment is moved quietly. Ambient staff voices are very soft. There is no radio; alarms are muted. Proximity to faucets and sinks, x-ray screens, telephone, and staff movement is avoided or their use is muted and quiet.

(5)   Sounds are consistently very low. Walls appear sound-reducing and absorbing. Monitors and telephones are on the lowest settings and with very soft rings, backing-up light and vibrating alarms. Staff voices are very quiet. Rounds occur away from the bedside. Overall, the infant's care area is peaceful and quiet.

3. Activity level

(1)   The nursery atmosphere is hectic with continuously changing activity, visitors, staff, technical and laboratory personnel hurrying about, water running, doors opening and closing and equipment being moved.

(2)   Activity levels are quite high, though at times subsiding to lower intensities.

(3)   Activity levels are moderately low. There appear to be efforts to move activity away from the infant's bedspace, although this appears to be inconsistent.

(4)   A calm, quiet nursery atmosphere is largely present; an exception may be an emergency situation.

(5)   A very calm, quiet, and soothing atmosphere is consistently present. Emergency situations are handled with an activity containing protocol.

4. Visual array inside of incubator/crib space

(1)   A complex and dense array of visual stimuli is continuously present on the walls of the crib or incubator; it may include numerous or intensely-patterned (e.g., black and white checkerboard) toys and mobiles continuously within the infant's immediate visual field; or the infant's visual space is filled with equipment and bedding only, without apparent consideration of the infant's visual experience or state organization; or the infant's visual field is barren and essentially devoid of texture, form, and color.

(2)   Many visual inputs are continuously present within the infant's immediate visual field, be they equipment or toys, mobiles, etc.; or the infant's visual space is nearly devoid of all texture, form, and color.

(3)   Several visual stimuli are continuously present within the infant's immediate visual field.

(4)   Visual stimuli are provided, including the parents and/or professional caregiver's face, when the infant is alerting. They are muted or removed from the infant's visual field when the infant becomes drowsy, is going to sleep, or becomes hyper-alert or upset.

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(5) Differential visual stimuli, including the parents and/or professional caregiver's face, are provided, muted, and removed in support of the infant's state and self-regulatory robustness.

5. Olfactory Inputs

(1) Noxious odors are frequently present in the infant's immediate olfactory field, e.g., alcohol wipes, adhesive remover, cleaning fluids, recent painting, caregivers' perfumes, cooking odors; soiled clothing; rubber tubings, gloves, equipment and disposable staff gowns. Familial and comforting odors, such as the mother's breast and body scent, the father's body scent, are absent.

(2) Noxious odors are periodically present in the infant's immediate olfactory field; familial, comforting odors are available when the parents are near the infant.

(3) Noxious odors are infrequently present in the infant's immediate olfactory field; familial, comforting odors are available when the parents hold the infant.

(4) Noxious odors are actively eliminated from the infant's immediate olfactory field whenever possible; a familial, comforting olfactory environment is provided for some of the time also when the infant is in the incubator or crib by providing the mother's breast pad, a blanket cloth, or piece of clothing the mother or father have worn or held on their body.

(5) A consistent familial olfactory environment of the parent's body scent is provided for the infant at all times.

6. Bedding and clothing

(1) Bedding and clothing are unrelated to the infant's individual needs or preferences; the infant may be unclothed and uncovered, and may be lying on a flat bedding surface; or the infant wears a disproportionately large diaper, or is completely and very tightly swaddled.

(2) Bedding and clothing are somewhat related to the infant's preferences and needs, e.g., the infant may be swaddled once cared for; however, swaddling may be tight or routinely applied; the infant's diaper and clothing may be too large for the infant; some nesting and boundaries may be used, apparently routinely.

(3) Bedding and clothing are in general related to the infant's preferences and needs, yet this is inconsistent, e.g., the infant may wear a hat and socks and has a foot roll, although it is not clear how these relate to the infant's organization. Holding of the infant by the parents for limited periods may be considered appropriate.

(4) Bedding and clothing are consistently related to the infant's preferences and needs and are individualized. This includes provision of options such as water mattress, sheepskin, boundaries, "nesting," clothing with soft one-piece suits, soft hat, gentle swaddling, and appropriately bedding the infant, and/or providing skin-to-skin holding by the parents for extended periods.

(5) Bedding and clothing is creatively individualized to suit the infant's needs; this includes the option of a bunting, hammock, huggel suckel, and/or huggel visor, as well as other individualized materials supportive of the infant, such as an appropriately soft and small diapers, well-fitting, soft clothing, and soft cover blankets. The parent is seen as the infant's most well-aligned bed; rooming-in with the infant is encouraged.

7. Specific self-regulatory aids

(1) Self-regulatory aids and use of buntings and pacifiers; being held by the parents or caregiver; human facilitation of containment and hand swaddling; opportunity to suckle on the parent's breast and/or caregiver's finger; are absent.

(2) Self-regulatory aids are occasionally or sporadically used.

(3) Self-regulatory aids are used frequently, yet uniformly and routinely. The parent is encouraged at times to provide regulation.

(4) Self-regulatory aids are used frequently and in an individualized fashion, including holding, human facilitations with hand swaddling, caressing, and containment, opportunities to suck during and between procedures such as gavage feedings; and to hold on during manipulations, using the caregiver's finger, bedding, foot rolls, and buntings. The parents are seen as the infant's best regulators. The professional caregiver encourages the parents' regulatory collaboration.

(5) Self regulatory aids are used consistently, and in an individualized fashion. This includes consistent parent skin-to-skin facilitation, and extensive holding and regulation by the professional caregiver when the parent is not in a position to be with the infant.

Infant's Name _____   Hospital/Level _____
Date _____   Caregiver _____
Time _____   Discipline _____
Medical Record # _____ Room/Nursery Census _____
Other Notes   Acuity/Room Census _____
                                  Observer(s) _____

Profile of the Nursery Environment and of Care Components
Template Score Sheet — Part I

A. Physical environment of the nursery

1. Location in relation to Labor and Delivery Floor and Mother's Postpartum Room	1	2	3	4	5	NA
2. Appearance	1	2	3	4	5	NA
3. Physical Layout	1	2	3	4	5	NA
4. Density and Size of Bedside Space	1	2	3	4	5	NA
5. Design of Bedside Space	1	2	3	4	5	NA
6. Conduciveness to Enhance Family Participation	1	2	3	4	5	NA
7. Conduciveness to Enhance Professional Care Components	1	2	3	4	5	NA

B. Physical Environment of the Infant's Bedspace

1. Light Level	1	2	3	4	5	NA
2. Sound Level	1	2	3	4	5	NA
3. Activity Level	1	2	3	4	5	NA
4. Visual Array Inside of Incubator/Crib Space	1	2	3	4	5	NA
5. Olfactory Inputs	1	2	3	4	5	NA
6. Bedding and Clothing	1	2	3	4	5	NA
7. Specific Self-Regulatory Aids	1	2	3	4	5	NA

APPENDIX H

CONSENT TO PARTICIPATE IN RESEARCH

IRB NUMBER: 205435050613

LOYOLA UNIVERSITY CHICAGO
HEALTH SCIENCES DIVISION
MAYWOOD, ILLINOIS
DEPARTMENT OF NEONATOLOGY

INFORMED CONSENT

Participant's Name:

_____

Medical Record Number:

_____

PROJECT TITLE: LU 205435 Mother-infant relationships in the NICU: A mulitple case study

THE APPROVAL FOR THIS PROJECT EXPIRES ON 04/30/2015.

Participant Information

PRINCIPLES CONCERNING RESEARCH: You are being asked to take part in a research project. It is important that you read and understand the principles that apply to all individuals who agree to participate in the research project described below:

1. Taking part in the research is entirely voluntary.

2. You will not benefit from taking part in the research but the knowledge obtained may help others.

3. You may withdraw from the study at any time without anyone objecting and without penalty or loss of any benefits to which you are otherwise entitled.

The purpose of the research, how it is to be done, and what your part in the research will be is described below. Also described are the risks, inconveniences, discomforts and other important information which you need to make a decision about whether or not you wish to participate. You are urged to discuss any questions you have about this research with the staff members.

PURPOSE OF RESEARCH: You are being asked to participate in this study because you have an infant hospitalized in the Newborn Intensive Care Unit at Loyola University Medical Center.

This purpose of this study is to (1) better understand the mother-infant relationship within the context of the Newborn Intensive Care Unit; (2) document how mothers' NICU experiences impact their understanding of themselves as mothers and their understanding of their infant.

This research is sponsored by Loyola University.

Approximately 5 people will participate in this research.

DESCRIPTION AND EXPLANATION OF PROCEDURES: If you agree to participate in this study, you will be asked to:

• Participate in three separate interviews during your child's stay in the NICU. You will be asked about how you think and feel about your child, and your relationship with him or her. Each interview will last about an hour and will be at a time and location of your choosing (total of three hours). If you would like to complete the interview while visiting your child, a private room located in the NICU will be provided.

• Allow the researcher to observe you feeding your baby (bottle or breast)

• Allow the researcher to access your infant's medical records in order to keep track of his/her health as it relates to the topic being studied.

• Complete questionnaires in order to provide demographic information, and information regarding how you have been feeling during this process (total time will be 1 and ½ hours at the most).

You will need to come to come to the NICU four times over the course of your infant's hospitalization. Each of those visits will take about an hour.

RISKS/DISCOMFORTS: There are no foreseeable risks involved in participating in this research. Although the overall format of the interviews and observations will be structured so that they are sensitive to the participant's needs, there is a possibility that the types of questions asked during the interview process may evoke feelings of uncertainty or discomfort. Every effort will be made to make you feel comfortable during the interview process. If you should need to speak with a mental health professional, you will be referred to the NICU social worker for this service. There may be a minor risk of loss of patient confidentiality.

BENEFITS: You will not benefit from participating in this study. The information learned may help others.

ALTERNATIVE TREATMENTS: You do not have to participate in this research project to receive care and treatment at Loyola University Medical Center.

FINANCIAL INFORMATION. There is no cost to you in participating in this research.

Upon completion of the interviews and feeding observation you will be given a $25 gift card to Target Stores.

INFORMATION COLLECTED AND WHAT WILL HAPPEN TO IT: In order to meet the goals of the research study (see Purpose of Research section of this consent), we will collect the following information on you and your baby, Loyola University Medical Center (LUMC) medical records. The information will be collected by Dr. Muraskas the principle investigator, the study physician(s), the research nurses, data administrators and secretaries.

Information about you will be provided to Loyola University Chicago; data collection and study verification agencies; and/or government regulatory agencies such as the Food and Drug Administration.

In this way, we will learn about how mother's of premature infants hospitalized in the NICU understand themselves as mothers and their relationship with their infants
The information we will collect and send includes:

_X___ DEMOGRAPHIC INFORMATION (e.g., name, address, phone number)

_X__ MEDICAL RECORD (including, but not limited to, history and physical exam notes, progress notes, consultation reports, laboratory test results, AND/OR operative reports)

We will collect and provide this information about you and your baby till the study ends.

Once the information is disclosed outside of LUMC, it may no longer be protected by federal privacy laws.

It is possible that the sponsor, Loyola University Chicago, research nurses, data collection and/or study verification agencies, data administrators or staff, or the Food and Drug Administration will come to LUMC and view the medical record (see above for description of content) and the research records. They may take notes or copy pages of the medical record. This is done to verify the accuracy of the information LUMC is sending to them.

The results of this research study may be published in a journal for the purpose of advancing medical knowledge. You will not be identified by name or by any other identifying information in any publication or report about this research.

Consent for LUMC to use and disclose your medical information is required in order for you to participate in the study.

WITHDRAWAL OF CONSENT: Your consent to use and disclose your medical information for the purpose of this research study is completely voluntary. You can withdraw your consent for LUMC to use and disclose your information and your consent to participate in this study at any time without affecting your ability to receive care and treatment at LUMC unrelated to the research study. Withdrawal means that all study procedures and follow-up will stop and we will not send any more information about you to the sponsor of this research or its designees. However, information already used and disclosed to the research sponsor prior to the time of your withdrawal from this study may continue to be used and disclosed by LUMC and the sponsor.

If you withdraw from the study, we will ask that you sign the form attached to this consent and send it to Dr. Muraskas or give it to the study staff. Your withdrawal from the study will not have any affect on any actions by LUMC taken before the attached form is received by LUMC.

Your study doctor, the Institutional Review Board, the regulatory authorities, or the sponsor, Loyola University, may terminate the study at any time with or without your consent.

CONSENT

I have fully explained to _____ the nature and purpose of the above- described procedure and the risks that are involved in its performance. I have answered and will answer all questions to the best of my ability. I may be reached at 708-216-1067.

_____Date:____/_____/____
Signature

Dr. Muraskas, the principal investigator for this study, or his associates will be available to answer any questions you may have. Dr. Muraskas can be reached at: 708-216-1067.

If you ever feel that you have been injured by participating in this study or if you have any questions concerning your rights as a research participant, you may contact either Kenneth Micetich, MD, Chair of the Institutional Review Board for the Protection of Human Subjects-Loyola University Chicago Health Sciences Division, at 708-216-2633 or Elaine Fluder, MSN, Director of the Human Research Subjects Protection Program at 708-216-4608.

Although you have the right to revoke this authorization, you accept that such revocation will not apply to any uses and disclosures of your information that are described in the Loyola University Health System Notice of Privacy Practices or otherwise allowable under any Federal or State laws.

You will receive a signed copy of this informed consent document.

You have been fully informed of the above-described research program with its possible benefits and risks. Your signature below indicates that you are willing to participate in this research study and agree to the use and disclosure of information about you as described above. You do not give up any of your legal rights by signing this consent document.

_____Date:____/_____/____
Signature: Participant

_____Date:____/_____/____
Signature: Witness

PROJECT TITLE: LU 205435 Mother-infant relationships in the NICU: A multiple case study approach

<div align="center">

REVOCATION OF AUTHORIZATION TO
RELEASE PROTECTED HEALTH INFORMATION (PHI)

</div>

I, _____, hereby revoke my consent to participate in the study titled, "Mother-infant relationships in the NICU: A multiple case study approach", at Loyola University Medical Center ("LUMC"). I also revoke my consent to release information I provided to LUMC that allowed LUMC to use and disclose my medical information to Dr. Muraskas as outlined on the consent form, which I signed on ____/_____/____ (INSERT DATE CONSENT WAS SIGNED ORIGINALLY). I understand that this revocation does not apply to any action LUMC has taken in reliance on the consent I signed earlier.

_____Date:____/_____/____
Signature: Participant

Please return this form to:

Dr. Muraskas
Loyola University Medical Center
2160 South First Avenue
Maywood, Illinois 60153

REFERENCE LIST

Abela, J. R. Z., Hankin, B. L., Haigh, E. A. P., Vinokuroff, T., Trayhern, L., & Adams, P. (2005). Interpersonal vulnerability to depressive episodes in high risk children: The role of insecure attachment and reassurance seeking. *Journal of Clinical Child and Adolescent Psychology, 34*, 182-192.

Abela, J. R. Z., Zinck, S., Kryger, S., Zilber, I., & Hankin, B. L. (2009). Contagious depression: Negative attachment cognitions as a moderator of the temporal association between parental depression and child depression. *Journal of Clinical Child and Adolescent Psychology, 38*, 16-26.

Aber, J. L., Slade, A., Bresgi, I., & Kaplan, M. (1985). *Parent development interview*. Unpublished Manuscript. Barnard College.

Affleck, G., Tennen, H., & Rowe, J. (1991). *Infants in crisis: How parents cope with newborn intensive care and its aftermath*. New York: Springer-Verlag.

Affonso, D. D., Hurst, I., Mayberry, L. J., & Haller, L. (1992). Stressors reported by mothers of hospitalized premature infants. *Neonatal Network, 11*(6), 63-70.

Ainsworth, M., Blehar, M. C., & Walters, E. (1978). *Patterns of attachment: A psychological study of the Strange Situation*. Hillsdale, NJ: Erlbaum.

Ainsworth, M. D. S., & Eichberg, C. G. (1991). Effects on infant-mother attachment of mother's unresolvd loss of an attachment figure or other traumatic experiences. In P. Marris, J. Stevenson-Hinde, & C. Parkes (Eds.), *Attachment across the life cycle* (pp. 160-183). New York: Routledge.

Als, H. (1982). Toward a synactive theory of development: Promise for the assessment and support of infant individuality. *Infant Mental Health Journal, 3*(4), 229-243.

Als, H. (1992). Individualized, family-focused developmental care for the very low birthweight preterm infant in the NICU. In S. L. Friedman, & M. D. Sigman (Eds.), *Advances in applied developmental psychology* (Vol. 6, pp. 341-388). Norwood, NJ: Ablex Publishing Company.

Als, H. (2009). NIDCAP: Testing the effectiveness of a relationship-based comprehensive intervention. *Pediatrics, 124*(4), 1208-1210.

Als, H., Buehler, D. M., Kerr, D., Feinberg, E., & Gilkerson, L. (1997). *Profile of the nursery environment and care components*. Template Manual, Children's Hospital Boston.

Als, H., Duffy, F. H., & McAnulty, G. B. (1988). Behavioral differences between preterm and full-term newborns as measured with the APIB system scores. *Infant Behavior and Development, 11*3, 305-318.

Als, H., Duffy, F. H., McAnulty, G. B., Rivkin, M. J., Vajapeyam, S., Mulkern, R. V., . . . Eichenwald, E. C. (2004). Early experience alters brain function and structure. *Pediatrics, 113*(4), 846-857.

Als, H., Gilkerson, L., Duffy, F. H., McAnulty, G. B., & Buehler, D. M. (2003). A three-center, randomized, controlled trial of individualized developmental care for very low birth weight preterm infants: medical, neurodevelopmental, parenting, and caregiving effects. *Developmental and Behavioral Pediatrics, 24*(6), 399-408.

Als, H., Lawhon, G., Duffy, F. H., McAnulty, G. B., Gibes-Grossman, R., & Blickman, J. G. (1994). Individualized developmental care for the very low birth weight preterm infant: Medical and neuronal effects. *JAMA, 272*(11), 853-858.

Ammaniti, M., Baumgartner, E., Candelori, C., Perucchini, P., Pola, M., Tambelli, R., & Zampino, F. (1992). Representations and narratives during pregnancy. *Infant Mental Health Journal, 13*(2), 167-182.

Anand, K. J. (2000). Pain, plasticity, and premature birth: a prescription for permanent suffering? *Nature Medicine, 6*(9), 971-973.

Andersen, P. A., & Telleen, S. L. (1992). The relationship between social support and maternal behaviors and attitudes: A meta-analytic review. *American Journal of Community Psychology, 20*(6), 753-774.

Arockiasamy, V., Holsti, L., & Albersheim, S. (2008). Fathers' expereinces in the neonatal intensive care unit: A search for control. *Pediatrics, 121*(2), e215-e223.

Atkinson, L., Paglia, A., Coolbear, J., Niccols, A., Parker, K. C., & Guger, S. (2000). Attachment security: A meta analysis of maternal mental health correlates. *Clinical Psychology Review, 20*, 1019-1040.

Avan, B., Richter, L. M., Ramchandani, P. G., Norris, S. A., & Stein, A. (2010). Maternal postnatal depression and children's growth and behaviour during the early years of life: exploring the interaction between physical and mental health. *Arch Dis Child, 95*, 690-695.

Baker, G. R., King, H., MacDonald, J. L., & Horbar, J. D. (2003). Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Pediatrics, 111*(Supplement E1), e419-e425.

Baum, N., Weidberg, Z., Osher, Y., & Kohelet, D. (2012). No longer pregnant, not yet a mother: Giving birth prematurely to a very-low-birth-weight baby. *Qual Health Res, 22*(5), 595-606. doi: 10.1177/1049732311422899

Belsky, J., Rosenburger, K., & Crnic, K. (1995). Maternal personality, marital quality, social support and infant tempearament: Their significance for infant-mother attachment in human families. In C. R. Pryce, R. D. Martin, & K. Crnic (Eds.), *Motherhood in human and nonhuman primates* (pp. 115-124). Basel, Switzerland: Karger.

Benoit, D., & Parker, K. C. (1994). Stability and transmission of attachment across three generations. *Child Development, 65*, 1444-1456.

Benoit, D., Parker, K. C., & Zeanah, C. H. (1997). Mother's representations of their infants assessed prenatally: Stability and association with infants' attachment classifications. *Journal of Child Psychology and Psychiatry, 38*(3), 307-313.

Berryman, J. C., & Windridge, K. C. (1996). Pregnancy after 35 and attachment to the fetus. *Journal of Reproductive and Infant Psychology, 14*, 133-143.

Biringen, Z., Robinson, J. L., & Emde, R. N. (2000). Appendix B: The Emotional Availability Scales (3rd ed.; an abridged Infancy/Early Childhood Version). *Attachment and Human Development, 2,* 256-270.

Bloom, K. C. (1995). The development of attachment behaviors in pregnant adolescents. *Nursing Research, 44*, 284-288.

Borghini, A., Pierrehumbert, B., Miljkovitch, R., Muller-Nix, C., Forcada-Guex, M., & Ansermet, F. (2006). Mother's attachment representations of their premature infant at 6 and 18 months after birth. *Infant Mental Health Journal, 27*(5), 494-508.

Bowlby, J. (1969/1982). *Attachment and loss: Vol. 1. Attachment*. New York: Basic Books.

Bowlby, J. (1988). *A secure base: Parent child attachment and healthy human development*. New York: Basic Books.

Bracht, M., O'Leary, L., Lee, S. K., & O'Brien, K. (2013). Implementing family-integrated care in the NICU: A parent education and support program. *Adv Neonatal Care, 13*(2), 115-126. doi: 10.1097/ANC.0b013e318285fb5b

Brandt, P. A., & Weinert, C. (1981). The PQR-a social support measure. *Nursing Research, 30*, 277-280.

Brazelton, B. (1974). Does the neonate shape his environment. *Birth defects: The infant at Risk, 10*, 131-140.

Brazelton, B. (1982). Joint regulation of neonate-parent behavior. In E. Tronick (Ed.), *Social interchanges in infancy: Affect, cognition, and communication*. Baltimore, MD: University Park Press.

Bretherton, I., Biringen, Z., Ridgeway, D., Maslin, C., & Sherman, M. (1989). Attachment: The parental perspective. *Infant Mental Health Journal, 10*, 203-221.

Bretherton, I., & Munholland, K. (1999). Internal working models in attachment relationships: A construct revisited. In J. Cassidy, & P. Shaver (Eds.), *Handbook of Attachment* (pp. 89-111). New York: Guilford Press.

Brisch, K.-H., Bechinger, D., Betzler, S., Heinemann, H., Kachele, H., Pohlandt, F., . . . Buchheim, A. (2005). Attachment quality in very low-birthweight premature infants in relation to maternal attachment representations and neurological development. *Parenting: Science and Practice, 5*(4), 311-331.

Bronfenbrenner, U. (2005). Strengthing family systems. In U. Bronfenbrenner (Ed.), *Making human beings human: Bioecological perspectives on human development* (pp. 260-273). London: Sage Publications.

Bronfenbrenner, U. (1979). *The ecology of human development*. Cambridge, MA: Harvard University Press.

Browne, J., & Talmi, A. (2005). Family-based intervention to enhance infant-parent relationships in the neonatal intensive care unit. *Journal of Pediatric Psychology, 30*(8), 667-677.

Byng-Hall, J. (1999). Family and couple therapy: Toward greater security. In J. Cassidy, & P. R. Shaver (Eds.), *Handbook of attachment, Theory, research and clinical applications* (pp. 625-648). New York: Guilford.

Callery, P. (2002). Mothers of infants in neonatal nurseries had challenges in establishing feels of being a good mother. *Evidence-Based Nursing, 5*(1), 91-92.

Caplan, G., Mason, E. A., & Kaplan, D. M. (1965). Four studies of crisis in parents of prematures. *Community Mental Health Journal, 1*(2), 149-161.

Carnelley, K. B., Pietromonaco, P. R., & Jaffe, K. (1994). Depression working models of others, and relationship functioning. *Journal of Personality and Social Psychology, 66*, 127-140.

Casillas, A., & Clark, L. (2000). *The Mini Mood and Anxiety Symptom Questionnaire (Mini-MASQ)*. Paper presented at the 72nd Annual Meeting of the Midwestern Psychological Association, Chicago, IL.

Cassidy, J. (2001). Truth, lies and intimacy: An attachment perspective. *Attachment and Human Development, 3*(2), 121-155.

Cerro, N., Zeunert, S., Simmer, K. N., & Daniels, L. A. (2002). Eating behavior of children 1.5-3.5 years born preterm: parents' perceptions. *Journal of Paediatrics and Child Health, 38*(1), 72-78.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine, 38*, 300-314.

Cohen, L. J., & Slade, A. (2000). The psychology and psychopathology of pregnancy: Reorganization and transformation. In C. Zeanah (Ed.), *Handbook of infant mental health* (2nd ed., pp. 20-36). New York: The Guilford Press.

Condon, J. T., & Corkindale, C. (1997). The correlates of antenatal attahcment in pregnant women. *British Journal of Medical Psychology, 70*, 359-372.

Cooper, L. G., Gooding, J. S., & Gallagher, J. (2007). Impact of family-centered care initiative on NICU care, staff and families. *Jouranl of Perinatology, 27*, S32-S37.

Coppola, G., & Cassibba, R. (2010). Mothers' social behaviours in the NICU during newborns' hospitalisation: an observational approach. *Journal of Reproductive and Infant Psychology, 28*(2), 200-211. doi: 10.1080/02646830903298731

Corter, C., & Minde, K. (1987). Impact of infant prematurity on family systems. *Advances in Developmental and Behavioral Pediatrics, 8*, 1-48.

Cramer, B., & Stern, D. (1988). Evaluation of changes in mother-infant brief psychotherapy. *Infant Mental Health Journal, 9*(1), 20-45.

Cranley, M. S. (1981). Development of a tool for the measurement of maternal attachment during pregnancy. *Nursing Research, 30*, 281-284.

Crittenden, P. (1988). Relationships at risk. In J. Belsky & T. Nezworski (Eds.), *Clinical implications of attachment* (pp. 136-174). London: Lawrence Erlbaum Associates.

Crnic, K., Greenberg, M. T., Ragozin, A. S., Robinson, N. M., & Basham, R. B. (1983). Effects of stress and social support on mothers and premature and full-term infants. *Child Development, 54*, 209-217.

Crnic, K., Greenberg, M. T., & Slough, N. M. (1986). Early stress and social support influences on mothers' and high-risk infants' functioning in late infancy. *Infant Mental Health Journal, 7*, 19-33.

Crockenberg, S. (1981). Infant irritablility, mother responsiveness, and social support influences on the security of infant-mother attachment. *Child Development, 52*(857-865).

Crockenberg, S. (1986). Are temperamental differences in babies associated with predictable differences in caregiving? *New Directions in Child Development, 54*, 209-217.

Davis, L., Edwards, H., Mohay, H., & Wollin, J. (2003). The impact of very premature birth on the psychological health of mothers. *Early Human Development, 73*, 61-70.

Dawson, G., Ashman, S. B., Panagiotides, H., Hessl, D., Self, J., & Yamada, E. (2003). Preschool outcomes of children of depressed mothers: Role of maternal behavior, contextual risk, and children's brain activity. *Child Development, 74*, 1158-1175.

DeGangi, G. A., Porges, S. W., Sickel, R. Z., & Greenspan, S. (1993). Four year follow up of a sample of regulatory disordered infants. *Infant Mental Health Journal, 14*(4), 330-343.

DeMier, R. L., Hynan, M. T., Hatfield, R. F., Varner, M. W., Harris, H. B., & Manniello, R. L. (2000). A measurement model of perinatal stressors: Identifying risk of postnatal emotional distress in mothers of high risk infants *Journal of clinical psychology, 56*(1), 89-100.

DiVitto, B., & Goldberg, S. (1979). The effects of newborn medical status on early parent-infant interaction. In T. M. Field (Ed.), *Infants born at risk* (pp. 311-332). Jamaica, NY: Spectrum.

Donovan, W. L., & Leavitt, L. A. (1985). Stimulating conditions of learned helplessness: The effects of interventions and attributions *Child Development, 56*, 594-603.

Dyer, K. A. (2005). Identifying, understanding, and working with grieving parents in the NICU, part II: strategies. *Neonatal Network, 24*(4), 27-40.

Easterbrooks, M. (1989). Quality of attachment to mother and father: Effects of perinatal risk status. *Child Development, 60*, 825-831.

Easterbrooks, M. A. (1988). Effect of infant risk status on the transition to parenthood. In G. Y. Michaels & W. A. Godlberg (Eds.), *The transition to parenthood: Current theory and research* (pp. 176-208). New York: Cambridge University Press.

Eckerman, C. O., Oehler, J. M., Medvin, M. B., & Hannan, T. E. (1994). Premature newborns as social partners before term age. *Infant Behavior and Development, 17*(1), 55-70.

Emde, R. N. (1989). The infant's relationship experience: Developmental and affective aspects. In A. Sameroff, & R. N. Emde (Eds.), *Relationship disturbances in early childhood* (pp. 33-51). New York: Basic Books.

Erikson, E. H., & Erikson, J. (1998). *The life cycle completed* New York: Norton.

Eriksson, B. S., & Pehrsson, G. (2002). Evaluation of psycho-social support to parents with an infant born preterm. *Journal of Child Health Care, 6*(1), 19-33.

Feeley, N., Zelkowitz, P., Cormier, C., Charbonneau, L., Lacroix, A., & Papageorgiou, A. (2011). Posttraumatic stress among mothers of very low birthweight infants at 6 months after discharge from the neonatal intensive care unit. *Applied Nursing Research, 24*(2), 114-117. doi: 10.1016/j.apnr.2009.04.004

Feldman, R., & Eidelman, A. I. (2006). Neonatal state organization, neuromaturation, mother-infant interaction, and cognitive development in small-for-gestational-age premature infants. *Pediatrics, 118*(3), e869-e878.

Feldman, R., & Eidelman, A. I. (2007). Maternal postpartum behavior and the emergence of infant-mother and infant-father synchrony in preterm and full-term infants: the role of neonatal vagal tone. *Developmental Psychobiology, 49*(3), 290-302.

Feldman, R., Eidelman, A. I., & Sirota, L. (2002). Comparison of skin-to-skin (kangaroo) and traditional care: parenting outcomes and preterm infant development. *Pediatrics, 110*, 16-26.

Feldman, R., Weller, A., Leckman, J. F., Kuint, J., & Eidelman, A. I. (1999). The nature of the mother's tie to her infant: maternal bonding under conditions of proximity, separation, and potential loss. *Journal of Child Psychology and Psychiatry, 40*, 929-939.

Feldman, R., Weller, A., Sirota, L., & Eidelman, A. I. (2003). Testing a family intervention hypothesis: The contribution of mother infant skin-to-skin contact (Kangaroo Care) to family interaction, proximity and touch. *Journal of Family Psychology, 17*(1), 94-107.

Fenwick, J., Barclay, L., & Schmied, V. (2001). Struggling to mother: A consequence of inhibitive nursing interactions in the neonatal nursery. *Journal of Perinatal and Neonatal Nursing, 15*(2), 49-64.

Ferber, S., & Maklous, I. (2004). The effect of skin-to-skin contact (kangaroo care) shortly after birth on the neurobehavioral responses of the term new-born: a randomized, controlled trial. *Pediatrics*, 113.

Field, T. (Ed.). (2002). *Prenatal effects of maternal depression*. Washington, DC: American Psychological Association.

Fischer, G., & Riedesser, P. (1998). *Lehrbuch der psychotraumatologie [textbook of psychotraumatology]*. Munich, Germany

Fivush, R. (1997). Event memory in early childhood. In C. Hulme, & N. Cowan (Eds.), *The development of memory in childhood: Studies in developmental psychology* (pp. 139-161). Hove, England: Pscyhology Press.

Flacking, R., Ewald, U., Hedberg Nyqvist, K., & Starrin, B. (2006). Trustful bonds: A key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of vey preterm infants at a neonatal unit. *Social Science and Medicine, 62*, 70-80.

Flacking, R., Ewald, U., Nyqvist, K. J., & Starrin, B. (2005). Trustful bonds: A key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science and Medicine, 62*, 70-80.

Flacking, R., Lehtonen, L., Thomson, G., Axelin, A., Ahlqvist, S., Moran, V. H., . . . Closeness Experiences in the Neonatal Environment, G. (2012). Closeness and separation in neonatal intensive care. *Acta Paediatr, 101*(10), 1032-1037. doi: 10.1111/j.1651-2227.2012.02787.x

Fonagy, P., Steele, H., & Steele, M. (1991). Maternal representations of attachment during pregnancy predict the organization of infant-mother attachment at one year of age. *Child Development, 62*(5), 891-905.

Fonagy, P., Target, M., Steele, H., & Steele, M. (1998). *Reflective-functioning manual, version 5.0, for application to adult attachment interviews*. London: University College London.

Forcada-Guex, M., Pierrehumbert, B., Borghini, A., Moessinger, A., & Muller-Nix, C. (2006). Early dyadic patterns of mother-infant interactions and outcomes of prematurity at 18 months. *Pediatrics, 118*(1), 107-114.

Fraiberg, S., Adelson, E., & Shapiro, V. (1975). Ghosts in the nursery: A psychoanalytic approach to the problems of impaired infant-mother relationships. *Journal of the American Academy of Child Psychiatry, 14*(3), 387-421.

Garcia Coll, C. T., Lamberty, G., Jenkins, R., McAdoo, H. P., Crnic, K., Wasik, B. H., & Vazquez Garcia, H. (1996). An integrative model for the study of developmental competencies in minority children. *Child Development, 67*(5), 1891-1914.

Garcia-Coll, C., & Meyer, E. C. (1993). The sociocultrual context of infant development. In C. Zeanah (Ed.), *The handbook of infant mental health* (pp. 56-69). New York: Guilford.

Garel, M., Dardennes, M., & Blondel, B. (2007). Mothers' psychological distress 1 year after very preterm childbirth. Results of the EPIPAGE qualitative study. *Child Care Health Dev, 33*(2), 137-143. doi: 10.1111/j.1365-2214.2006.00663.x

Gayle, G., & Vandenberg, K. A. (1998). Kangaroo care. *Neonatal Network, 17*, 69-71.

George, C., & Solomon, J. (1996). Representational modes of relationships: Links between caregiving and attachment. *Infant Mental Health Journal, 17*(3), 198-216.

Gerner, E. (1999). Emotional interaction in a group of preterm infants at 3 and 6 months of corrected age. *Infant Child Development, 8*, 117-128.

Gigliotti, E., & Samuels, W. E. (2011). Use of averaged norbeck social support questionnaire scores. *ISRN Nurs, 2011*, 567280. doi: 10.5402/2011/567280

Goldberg, S., Perrotta, M., & Minde, K. (1986). Maternal behavior and attachment in low-birth-weight twins and singletons. *Child Development, 57*(1), 34-46.

Gooding, J. S., Cooper, L. G., Blaine, A. I., Franck, L. S., Howse, J. L., & Berns, S. D. (2011). Family support and family-centered care in the neonatal intensive care unit: origins, advances, impact. *Seminars in perinatology, 35*(1), 20-28.

Goodman, S. H., & Brand, S. R. (Eds.). (2009). *Infants of depressed mothers: Vulnerabilities, risk factors, and protective factors for the later development of psychopathology* (3rd ed.). New York: Guilford Press.

Goodman, S. H., & Gotlib, I. H. (1999). Risk for psychopathology in the children of depressed mothers: A developmental model for understanding mechanisms of transmission. *Psychological Review, 106*, 458-490.

Goodman, S. H., & Gotlib, I. H. (Eds.). (2002). *Children of depressed parents: Mechanisms of risk and implications for treatment*. Washington, DC: American Psychological Association.

Grahm, C. A., & Easterbrooks, M. A. (2000). School-aged children's vulnerability to depressive symptomatology: The role of attachment security, maternal depressive symptomatology, and economic risk. *Development and Psychopathology, 12*, 201-213.

Greenberg, M. T., & Crnic, K. (1988). Longitudinal predictors of developmenal status and social interaction in premature and full-term infants at age two. *Child Development, 59*(3), 554-570.

Greenspan, S., & Wieder, S. (1993). Regulatory Disorders. In C. H. Zeanah (Ed.), *The handbook of infant mental health* (pp. 280-290). New York: Guilford.

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, CA: Sage.

Hall, E. T. (1977). *Beyond culture*. Garden City, NY: Anchor Press.

Hall, S., Hynan, M. T., Phillips, R., Press, J., Kenner, C., & Ryan, D. J. (2015). Development of program standards for psychosocial support of parents of infants admitted to a neonatal intensive care unit: A national interdisciplinary consensus model. *Newborn and Infant Nursing Reviews, 15*(1), 24-27.

Hamelin, K., & Ramachandran, C. (1993). Kangaroo care. *Canadian nurse, 89*(6), 15-16.

Hane, A. A., Myers, M. M., Hofer, M. A., & Ludwig, R. J. (2015). Family nurture intervention improves the quality of maternal caregiving in the neonatal intensive care unit: evidence from a randomized controlled trial. *Journal of Developmental and Behavioral Pediatrics, 36*(3), 188-196.

Heermann, J. A., Wilson, M. E., & Wilhelm, P. A. (2005). Mothers in the NICU: Outsider to partner. *Pediatric nursing, 31*(3), 176-181.

Heimer, C., & Staffen, L. (1998). *For the sake of the children: The social organization of responsibility in the hospital and the home*. Chicago, IL: University of Chicago Press.

Hesse, E. (1999). The Adult Attachment Interview: Histortical and current perspectives. In J. Cassidy, & P. Shaver (Eds.), *Handbook of attachment: Theory, research and clinical applications* (pp. 395-433). New York: Guilford Press.

Hill, J., Fonagy, P., Safier, E., & Sargent, J. (2003). The ecology of attachment in the family. *Family Process, 42*(2), 205-221.

Hofer, M. A. (1994). Hidden regulators in attachment, separation, and loss. *Monographs of the Society for Research in Child Development, 59*, 192-207.

Holditch-Davis, D., & Miles, M. S. (2000). Mothers' stories about their experiences in the neonatal intensive care unit. *Neonatal Network, 19*(3), 13-21.

Holditch-Davis, D., Miles, M. S., Weaver, M., Black, B., Beeber, L., Thoyre, S., & Engelke, S. (2009). Patterns of distress in African-American mothers of preterm infants. *Journal of Developmental and Behavioral Pediatrics, 30*(3), 193-205.

Hoyert, D. L., Mathews, T. J., Menacker, F., Strobino, D. M., & Guyer, B. (2006). Annual Summary of Vital Statistics: 2004. *Pediatrics, 117*, 168-183.

Hubert, N. C., Wachs, T. D., Peters-Martin, P., & Gandour, M. J. (1982). The study of early temperament. *Child Development, 53*, 571-600.

Hughes, M., McCollum, J., Sheftel, D., & Sanchez, G. (1994). How parents cope with the experience of neonatal intensive care. *Children's Health Care, 23*, 1-4.

Huhtala, M., Korja, R., Lehtonen, L., Haataja, L., Lapinleimu, H., & Rautava, P. (2012). Parental psychological well-being and behavioral outcome of very low birth weight infants at 3 years. *Pediatrics, 129*(4), e937-e944.

Huhtala, M., Korja, R., Lehtonen, L., Haataja, L., Lapinleimu, H., Rautava, P., & Group, P. S. (2014). Associations between parental psychological well-being and socio-emotional development in 5-year-old preterm children. *Early Human Development, 90*, 119-124.

Hurst, I. (2001a). Mothers' strategies to meet their needs in the newborn intensive care nursery. *Journal of Perinatal and Neonatal Nursing, 15*(2), 65-82.

Hurst, I. (2001b). Vigilant watching over: Mothers' actions to safegaurd their premature babies in the newborn intensive care nursery. *Journal of Perinatal and Neonatal Nursing, 15*(3), 39-57.

Jackson, K., Ternestedt, B. M., & Schollin, J. (2003). From alienation to familiarity: Experiences of mothers and fathers of preterm infants. *Journal of Advanced Nursing, 43*(2), 120-129.

Johnson, A. N. (2008). Engaging fathers in the NICU: Taking down the barriers to the baby. *Journal of perinatal & neonatal nursing, 22*(4), 302-306.

Jotzo, M., & Poets, C. F. (2005). Helping parents cope with the trauma of premature birth: An evaluation of a trauma-preventive psychological intervention. *Pediatrics, 115*(4 Part 1), 915-919.

Karatzias, T., Chouliara, Z., Maxton, F., Freer, Y., & Power, K. (2007). Post-traumatic symptomatology in parents with premature infants: a systematic review of the literature. *Journal of Prenatal and Perinatal Psychology and Health, 21*, 249-261.

Karen, R. (1998). *Becoming attached: First relationships and how they shape our capacity to love*. New York: Oxford University Press.

Kersting, A., Dorsch, M., & Wesselmann, U. (2004). Maternal post-traumatic stress response after the birth of a very low birthweight infant. *Journal of Psychosomatic Research, 57*(5), 473-476.

Klaus, M. H., & Klaus, P. H. (1985). *The amazing newborn: making the most of the first weeks of life.* Reading, MA: Addison-Wesley.

Kleberg, A., Hellstrom-Westas, L., & Widstrom, A. M. (2007). Mothers' perception of Newborn Individualized Developmental Care and Assessment Program (NIDCAP) as compared to conventional care. *Early Human Development, 83*(6), 403-411. doi: 10.1016/j.earlhumdev.2006.05.024

Kleberg, A., Westrup, B., Stjernqvist, K., & Lagercrantz, H. (2002). Indications of improved cognitive development at one year of age among infants born very prematurely who received care based on the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). *Early Human Development, 68*, 83-91.

Korja, R. (2009). *Early relationship between very preterm infant and mother: The role of infant, maternal and dyadic factors*. University of Turku. Turku, Finland.

Korja, R., Ahlqist-Bjorkroth, S., Savonlahti, E., Stolt, S., haataja, L., Lapinleimu, H., . . . Lehtonen, L. (2010). Relations between maternal attachment representations and the quality of mother-infant interaction in preterm and full-term infants. *Infant Behavior and Development, 33*, 330-336.

Korja, R., Savonlahti, E., Haataja, L., Lapinleimu, H., Manninen, H., Piha, J., & Lehtonen, L. (2009). Attachment representations in mothers of preterm infants. *Infant Behavior and Development, 32*, 305-311.

Lasiuk, G. C., Comeau, T., & Newburn-Cook, C. (2013). Unexpected: An interpretive description of parental traumas' associated with preterm birth. *BMC Pregnancy Childbirth, 13 Suppl 1*, S13. doi: 10.1186/1471-2393-13-S1-S13

Latva, R., Korja, R., Salmelin, R. K., Lehtonen, L., & Tamminen, T. (2008). How is maternal recollection of the birth experieince related to the behavioral and emotional outcome of preterm infants? *Early Human Development, 84*, 587-594.

Lau, R., & Morse, C. A. (2001). Parents' coping in the neonatal intensive care unit: a theoretical framework. *Journal of Psychosomatic Obstetrics and Gynecology, 22*(1), 41-47.

Lawhon, G. (2002). Facilitation of parenting the premature infant within the newborn intensive care unit. *Journal of Perinatal and Neonatal Nursing, 16*(1), 71-82.

Lerner, R. M., Dowling, E., & Chaudhuri, J. (2005). Methods of contextual assessment and assessing contextual methods: A developmental systems perspective. In D. M. Teti (Ed.), *Handbook of research methods in developmental science*. Malden, MA: Blackwell Publishing.

Lester, B. M., Boukydis, C. F. Z., Garcia Coll, C. T., & Hole, W. (1990). Colic for developmentalists. *Infant Mental Health Journal, 11,* 321-333.

Levine, L. V., Tuber, S. B., Slade, A., & Ward, M. J. (1991). Mothers' mental representations and their relationship to mother-infant attachment. *Bulletin of the Menninger Clinic, 55*, 454-469.

Levine, R. A. (1974). Parental goals: A cross-cultural view. *Teachers College Record, 76*, 226-239.

Lieberman, A. F. (1995). *The emotional life of the toddler*. New York: Free Press.

Loos, C., & Julius, L. (1988). The client's view of hospitalization during pregnancy. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 18*, 52-56.

Lucassen, P. L. B., Assendelft, W. J. J., van Eijk, J. T. M., & Gubbels, J. W. (2001). Systematic review of the occurance of infantile colic in the community. *Archives of Disease in Childhood, 84*, 398-403.

Lumley, J. M. (1982). Attitudes to the fetus among the primigravidae. *Australian Pediatric Journal, 18*, 106-109.

Lundqvist, P., Westas, L., & Hallstrom, I. (2007). From distance toward proximity: Fathers' lived experience of caring for their preterm infants. *Journal of Pediatric Nursing, 22*(6), 490-497.

Lupton, D., & Fenwick, J. (2001). 'They've forgotten that I'm the mum': Constructing and practicing motherhood in special care nurseries. *Social Science and Medicine, 53*, 1011-1021.

Lyons-Ruth, K., Connell, D., Grunebaum, H., & Botein, S. (1990). Infants at social risk: maternal depression and family support services as mediators of infant development and security of attachment. *Child Development, 61*, 85-98.

Macey, T. J., Harmon, R. J., & Easterbrooks, M. (1987). Impact of premature birth on the development of the infant in the family. *Journal of Consulting and Clinical Psychology, 55*(6), 846-852.

Main, M., & Goldwyn, R. (1984). *Adult attachment scoring and classification system.* Unpublished Manuscript. University of California at Berkeyley.

Main, M., & Goldwyn, R. (1990). *Interview-based adult attachment classifications: Related to infant-mother and infant-father attachment.*

Main, M., & Hesse, E. (1990). Parents unresolved traumatic experiences are related to infant disorganized attachment status: Is frightened and/or frightening parental behavior the linking mechanism? In M. T. Greenberg, & D. Cicchetti (Eds.), *Attachment in the preschool years* (pp. 161-182). Chicago, IL: University of Chicago Press.

Main, M., Kaplan, N., & Cassidy, J. (1985). Security in infancy, childhood, and adulthood: A move to the level of representation *Growing points of attachment theory and research. Monographs of the Society for Research in Child Development, 50*(1-2), 66-104.

Maloni, J. A., Kane, J. H., Suenm, L. J., & Wang, K. K. (2002). Dysphoria among high-risk pregnant hospitalized women on bed rest: A longitudinal study. *Nursing Research, 51*(2), 92-99.

Martin, J. A., Hamiton, B. E., Sutton, P. D., Ventura, S. J., Menacker, F., & Munson, M. L. (2005). Births: Final data for 2003. *National Vital Statistics Reports, 54*(2), 1-16.

Marvin, R. S., & Steward, R. B. (1990). A family systems framework for the study of attachment. In M. T. Greenberg, D. Cicchetti, & E. M. Cummings (Eds.), *Attachment in the preschool uyears: Theory, research and intervention* (pp. 51-86). Chicago, IL: University of Chicago Press.

McCain, G. C., & Deatrick, J. A. (1994). The experience of high-risk pregnancy. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 23*(5), 421-427.

McDonough, S. C. (2004). Interaction guidance: Promoting and nurturing the caregiving relationship. In A. J. Sameroff, S. C. McDonough, & K. L. Rosenblum (Eds.),

Treating parent-infant relationship problems: strategies for intervention (pp. 79-96). New York: Guilford Press.

McGrath, J. M., Samra, H. A., & Kenner, C. (2011). Family-centered developmental care practices and research: what will the next century bring? *Journal of Perinatal and Neonatal Nursing, 25*(2), 165-170. doi: 10.1097/JPN.0b013e31821a6706

Meijssen, D., Wolf, M., van Bakel, H., Koldewijn, K., Kok, J., & van Baar, A. (2011). Maternal attachment representations after very preterm birth and the effect of early intervention. *Infant Behavior and Development, 34*(1), 72-80.

Merkatz, R., Budd, K., & Merkatz, I. (1978). Psychologic and social implications of scientific care for pregnant diabetic women. *Seminars in Perinatology, 2*, 373-381.

Merriam, S. B. (2009). Qualitative case study research. In *Qualitative research: A guide to design and implementation* (pp. 39-54). San Francisco, CA: Jossey-Bass.

Meyer, E. C., Zeanah, C., Boukydis, C. F. Z., & Lester, B. M. (1993). A clinical interview for parents of high-risk infants: Concept and applications. *Infant Mental Health Journal, 14*(3), 192-207.

Mikulincer, M., & Shaver, P. R. (2008). Adult attachment and affect regulation. In J. Cassidy, & P. R. Shaver (Eds.), *Handbook of attachment: Theory, research and clinical applications* (pp. 503-531). New York: Guilford Press.

Miles, M. S., Funk, S. G., & Kasper, M. A. (1991). The neonatal intensive care unit environment: sources of stress for parents. *AACN Advanced Critical Care, 2*(2), 346-354.

Miles, M. S., & Holditch-Davis, D. (1995). Compensatory parenting: how mothers describe parenting their 3 year old prematurely born children. *Journal of Pediatric Nursing, 10*, 243-253.

Miles, M. S., Holditch-Davis, D., Schwartz, T. A., & Scher, M. (2007). Depressive symptoms in mothers of prematurely born infants. *Journal of Developmental and Behavioral Pediatrics, 28*(1), 36-44.

Miles, M. S., Wilson, S. M., & Docherty, S. L. (1999). African American mothers' responses to hospitalization of an infant with serious health problems. *Neonatal Network, 18*, 17-25.

Miller, P., & Sperry, L. (1987). The socialization of anger and aggression. *Merrill Palmer Quarterly, 33*(1), 1-31.

Minde, K. (2000). Prematurity and serious medical conditions in infancy: Implications for development, behavior and intervention. In C. Zeanah (Ed.), *Handbook of infant mental health* (pp. 176-194). New York: Guilford Press.

Minde, K., Corter, C., & Goldberg, S. (1985). The contribution of twinship and health to early interaction and attachment between premaure infants and their mothers. In S. L. Friedman & M. D. Sigman (Eds.), *The psychological development of low-birthweight children: Advances in applied developmental psychology* (pp. 157-185). Norwood, NJ: Ablex.

Minde, K., Perrotta, M., & Marton, P. (1985). Maternal caretaking and play with full-term and preterm infants. *Journal of Child Psychology and Psychiatry, 26*(2), 231-244.

Montirosso, R., Provenzi, L., Calciolari, G., & Borgatti, R. (2012). Measuring maternal stress and perceived support in 25 italian nicus. *Acta Paediatrica, 101*(2), 136-142.

Muller-Nix, C., Forcada-Guex, M., Pierrehumbert, B., Jaunin, L., Borghini, A., & Ansermet, F. (2004). Prematurity, maternal sress and mother-child interactions. *Early Human Development, 79*(2), 145-158.

Norbeck, J., Lindsey, A. M., & Carrieri, V. L. (1981). The development of an instrument to measure social support. *Nursing Research, 30*, 264-269.

Nystrom, K., & Axelsson, K. (2002). Mothers' experience of being separated from their newborns. *Journal of Obstetrics, Gynecology and Neonatal Nursing, 31*(3), 275-282.

Obeidat, H. M., Bond, E. A., & Callister, L. C. (2009). The parental experience of having an infant in the newborn intensive care unit. *The Journal of Perinatal Education, 18*(23-29).

Ogbu, J. U. (1981). Origins of human competence: A cultural-ecological perspective. *Child Development, 52*(2), 413-429.

Ohlinger, J., Brown, M. S., Laudert, S., Swanson, S., & Fofah, O. (2003). Development of potentially better practices for the neonatal intensive care unit as a culture of collaboration: communication, accountability, respect, and empowerment. *Pediatrics, 111*(4 Pt 2), e471-e481.

Papousek, M., & Von Hofacker, N. (1998). Persistent crying in early infancy: A non-trivial condition of risk for the developing mother-infant relationship. *Child Care Health and Development, 24*, 395-424.

Piaget, J., & Inhelder, B. (1969). *The psychology of the child*. New York: Basic books.

Pierrehumbert, B., Nicole, A., Muller-Nix, C., Forcada-Guex, M., & Ansermet, F. (2003). Parental post-traumatic reactions after premature birth: Implications for sleeping and eating problems in the infant. *Archives of Disease in Childhood Fetal Neonatal Edition, 88*(5), F400-F404.

Plunkett, J. W., Klein, T., & Meisels, S. J. (1988). The realtionship of preterm infant-mother attachment to stranger sociability at 3 years. *Infant Behavior and Development, 11*, 83-96.

Plunkett, J. W., Meisels, S. J., Stiefel, G. S., Pasick, P. L., & Roloff, D. W. (1986). Patterns of attachment among preterm infants of varying biological risk. *Journal of the American Academy of Child Psychiatry, 25*(6), 794-800.

Poehlmann, J., Schwichtenberg, A., Bolt, D., & Dilworth-Bart, J. (2009). Predictors of depressive symptom trajectories in others of preterm or low birth weight infants. *Journal of Family Psychology, 23*(5), 690-704.

Pohlman, S. (2005). The primacy of work and fathering preterm infants: Findings from an interpretive phenomenological study. *Advances in Neonatal Care, 5*(4), 204-216.

Raju, T. N. K. (2006). From infant hatcheries to intensive care: Some highlights of the century of neonatal medicine. In R. J. Martin, A. A. Fanaroff, & M. C. Walsh (Eds.), *Neonatal-perinatal medicine* (8th ed., Vol. 1, pp. 1-18). Philadelphia, PA: Mosby Elsevier.

Redshaw, M. E., & Harris, A. (1995). Maternal perceptions of neonatal care. *Acta Paediatrica, 84*(6), 593-598.

Righetti-Veltema, M., Conne-Perreard, E., Bousquet, A., & Manzano, J. (1998). Risk factors and predictive signs of postpartum depression. *Journal of Affective Disorders, 49*, 167-180.

Rode, S. S., Change, P., Nian, P., Fisch, R. O., & Sroufe, L. A. (1981). Attachment patterns of infants separated at birth. *Development Psychology, 17*, 188-191.

Rosenblum, K. L., Zeanah, C., McDonough, S., & Muzik, M. (2004). Video-taped coding of working model of the child interviews: a viable and useful alternative to verbatim transcripts? *Infant Behavior and Development, 27*(4), 544-549. doi: 10.1016/j.infbeh.2004.04.001

Rubin, H. R., Owens, A. J., & Golden, G. (1998). An investigation to determine whether the built environment affects patients' medical outcomes. *Report*. Martinez, CA: Center for Health Design.

Rubin, R. (1975). Maternal tasks in pregnancy. *Maternal-Child Nursing Journal, 4*, 143-153.

Sameroff, A. (2004). Ports of entry and the dynamics of mother-infant interventions. In A. J. Sameroff, S. C. McDonough, & K. L. Rosenblum (Eds.), *Treating parent-infant relationship problems: stategies for intervention* (pp. 3-28). New York: Guilford Press.

Sameroff, A., & Feise, B. H. (2000). Transactional regulation: The developmental ecology of early intervention. In J. P. Shonkoff, & S. J. Meisels (Eds.), *Handbook of early intervention* (pp. 135-159). New York: Cambridge University Press.

Schechter, D. S., Coots, T., Zeanah, C. H., Davies, M., Coates, S. W., Trabka, K. A., . . . Myers, M. M. (2005). Maternal mental representations of the child in an inner-city clinical sample: Violence-related posttraumatic stress and reflective functioning. *Attachment and Human Development, 7*(3), 313-331.

Schmucker, G., Brisch, K.-H., Kohntop, B., Betzler, S., Osterie, M., Pohlandt, F., . . . Buchheim, A. (2005). The influence of prematurity, maternal anxiety, and infant's neurobiological risk on mother-infant interactions. *Infant Mental Health Journal, 26*(5), 423-441.

Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3rd ed.). New York: Teachers College Press.

Shaker, C. (2010). Improving feeding outcomes in the NICU: moving from volume-driven to infant-driven feeding. *SIG 13 Perspectives on Swallowing and Swallowing Disorders Dysphagia, 19*(3), 68-74.

Shaw, R. J., Deblois, T., Ikuta, L., Ginzburg, K., & Fleisher, B. F. (2006). Acute stress disorder among parents of infants in the neonatal intensive care nursery. *Psychsomatics, 47*(3), 206-212.

Shin, H. J. (2004). Situational meaning and maternal self-esteem in mothers of high-risk newborns. *Journal of Korean Academy of Nursing, 34*(1), 93-101.

Singer, L. T., Guo, S., Collin, M., Lilien, L., & Baley, J. (1999). Maternal psychological distress and parenting stress after the birth of a very low birth weight infant. *JAMA, 281*, 799-805.

Singer, L. T., Salvator, A., Guo, S., Collin, M., Lilien, L., & Baley, J. (1999). Maternal psychological distress and parenting stress after the birth of a very low birth weight infant. *JAMA, 281*(9), 799-805.

Slade, A. (1999). Attachment theory and research: Implications for the theory and practice of individual psychotherapy with adults. In J. Cassidy, & P. Shaver (Eds.), *Handbook of attachment: Theory, research and clinical applications* (pp. 575-594). New York: Guilford Press.

Slade, A. (2005). Parental reflective functioning: An introduction. *Attachment and Human Development, 7*(3), 269-281.

Slade, A., & Cohen, L. J. (1996). The process of parenting and the remembrance of things past. *Infant Mental Health Journal, 17*(3), 217-238.

Slade, A., Cohen, L. J., Sadler, L. S., & Miller, M. (Eds.). (2009). *The psychology and psychopathology of pregnancy: Reorganization and transformation* (3rd ed.). New York: Guilford Press.

Slaikeu, K. A. (1990). *Crisis intervention: A handbook for practice and research*. Boston, MA: Allyn & Bacon.

Smith, J., Swallow, V., & Coyne, I. (2015). Involving parents in managing their child's long-term condition-a concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing, 30*(1), 143-159. doi: 10.1016/j.pedn.2014.10.014

Sokolowski, M. S., Hans, S. L., & Bernstein, V. J. (2010). Mothers' representations of their infants and parenting behavior: Associations with personal and social-contextual variables in a high-risk sample. *Infant Mental Health Journal, 28*(3), 344-365.

Solomon, J., & George, C. (1996). Defining the caregiving system: Towards a theory of caregiving. *Infant Mental Health Journal, 17*, 183-197.

Solomon, J., & George, C. (1999a). *Attachment disorganization*. New York: Guilford Press.

Solomon, J., & George, C. (1999b). The effects on attachment of overnight visitation in divorced and separated families: A longitudinal follow-up. In J. Solomon, & C. George (Eds.), *Attachment disorganization* (pp. 265-290). New York: Guilford Press.

Spradley, J. P. (1979). *The ethnographic interview*. New York: Holt, Rinehart & Winston.

Stack, D. M., & Muir, D. W. (1992). Adult tactile stimulation during face-to-face interactions modulates five-month-olds' affect and attention. *Child Development, 63*(6), 1509-1525.

Stake, R. (1995). *The art of case study research*. Thousand Oaks, CA: Sage Publications.

Stake, R. E. (1995). The nature of qualitative research. In *The art of case study research* (pp. 35-48). Thousand Oaks, CA: Sage.

Stake, R. E. (2006). Cross-case analysis. In *Multiple case study analysis* (pp. 39-77). New York: Guilford Press.

Stern, D. (2000). *The interpersonal world of the infant: A view from psychoanalysis and developmental psychology*. New York: Basic Books.

Stern, D. N. (1995). *The motherhood constellation: A unified view of parent-infant psychotherapy*. New York: Basic Books.

Stern, D., Bruschweiler-Stern, N., & Freeland, A. (1998). *The birth of a mother: How the motherhood experience changes you forever*. New York: Basic Books.

Stern-Bruschweiler, N., & Stern, D. N. (1989). A model for conceptualizing the role of the mothers representational world in various mother-infant therapies. *Infant Mental Health Journal, 10*(3), 142-156.

Stifter, C. A., & Bono, M. A. (1998). The effect of infant colic on maternal self-perceptions and mother-infant attachment. *Child: Care, Health and Development, 24*(5), 339-351.

Stjernqvist, K., & Svenningsen, N. W. (1990). Neurobehavioural development at term of extremely low-birthweight infants (less than 901g). *Developmental Medicine and Child Neurology, 32*(8), 679-688.

Swift, M. C., & Scholten, I. (2009). Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in a neonatal unit. *Journal of Clinical Nursing, 19*, 249-258.

Talmi, A., & Harmon, R. J. (2003). Relationship between preterm infants and their parents: Disruption and development. *Zero to Three*, 13-20.

Theran, S. A., Levendosky, A., Bogat, G. A., & Huth-Bocks, A. C. (2005). Stability and change in mothers' internal representations of their infants over time. *Attachment and Human Development, 7*(3), 253-268.

Thomas, A., & Chess, S. (1977). *Temperament and development*. New York: Brunner-Mazel.

Thoyre, S. M., Holditch-Davis, D., Schwartz, T. A., & Melendez, R. (2012). Coregulated approach to feeding preterm infatns with lung disease: Effects during feeding. *Nursing Research, 61*(4), 242-251.

Tooten, A., Hall, R. A., Hoffenkamp, H. N., Braeken, J., Vingerhoets, A. J., & van Bakel, H. J. (2014). Maternal and paternal infant representations: a comparison between parents of term and preterm infants. *Infant Behav Dev, 37*(3), 366-379. doi: 10.1016/j.infbeh.2014.05.004

Toth, S. L., Rogosch, F. A., Sturge-Apple, M., & Cicchetti, D. (2009). Maternal depression, children's attachment security, and representational development: An organizational perspective. *Child Development, 80*(1), 192-208.

Treyvaud, K., Lee, K. J., Doyle, L. W., & Anderson, P. J. (2014). Very preterm birth influences parental mental health and family outcomes seven years after birth. *Journal of Pediatrics, 164*(3), 515-521. doi: 10.1016/j.jpeds.2013.11.001

Tronick, E. (1980). On the primacy of social skills. In D. B. Sawin, L. O. Walker, & J. H. Penticuff (Eds.), *The exceptional infant: Psychosocial risks in infant-environmental transactions* (Vol. 4, pp. 144-158). New York: Brunner/Mazel.

Tronick, E. (1982). *Social interchange in infancy: Affect, cognition, and communication*. Baltimore, MD: University Park Press.

Tronick, E. (2007). The mutual regulation model: The infant's self and interactive regulation and coping and defensive capacities. In E. Tronick (Ed.), *The neurobehavioral and social-emotional development of infants and children* (pp. 177-194). New York: WW. Norton & Company, Inc.

van Ijzendoorn, M. H., Schuengel, C., & Bakersman-Kranenburg, M. J. (1999). Disorganized attachment in early childhood: Meta-analysis of precursors, concomitants, and sequelae. *Development and Psychopathology, 11*, 225-249.

Vandenberg, K. A., & Hanson, M. J. (2013). *Coming home from the NICU: A guide for supporting families in early infant care and development*. Baltimore: Paul H. Brookes Publishing Co.

Vandenberg, K. A. (2007). Individualized developmental care for high risk newborns in the NICU: A practice guideline. *Early Human Development, 83*(7), 433-442.

Vanderbilt, D., Bushley, T., Young, R., & Frank, D. A. (2009). Acute posttraumatic stress symptoms among urban mothers with newborns in the neonatal intensive

care unit: a preliminary study. *Journal of Developmental and Behavioral Pediatrics, 30*(1), 50-56.

Wallin, D. J. (2007a). Fonagy and forward. In D. J. Wallin (Ed.), *Attachment in psychotherapy* (pp. 43-58). New York: Guilford Press.

Wallin, D. J. (2007b). Nonverbal experience and the "unthought known": Accessing the emotional core of the self. In *Attachment in psychotherapy* (pp. 115-132). New York: Guilford Press.

Walsh, M. C., & Fanaroff, A. A. (2006). Epidemiology and Perinatal Services. In R. J. Martin, A. A. Fanaroff, & M. C. Walsh (Eds.), *Neonatal-perinatal medicine: Diseases of the fetus and infant* (8th ed., Vol. 1, pp. 19-34). Philadelphia, PA: Mosby Elsevier.

Ward, M. J., & Carlson, E. A. (1995). Associations among adult attachment representations, maternal sensitivity, and infant-mother attachment in a sample of adolescent mothers. *Child Development, 66*, 69-79.

Wayland, J., & Tate, S. (1993). Maternal-fetal attachment and perceived relationships with important others in adolescents. *Birth, 20*, 198-203.

Wereszezak, J., Miles, M. S., & Holditch-Davis, D. (1997). Maternal recall of the neonatal intensive care unit. *Neonatal Network, 16*(4), 33-40.

Wessel, M. A., Cogg, J. C., Jackson, E. B., Harris, G. S., & Detwiler, A. C. (1954). Paroxysmal fussing in infancy, sometimes called "colic". *Pediatrics, 14*, 421-434.

Westrup, B., Kleberg, A., von Eichwald, K., Stjernqvist, K., & Lagercrantz, H. (2000). A randomized controlled trial to evaluate the effects of the newborn individualized developmental care and assessment Program in a Swedish setting. *Pediatrics, 105*(1), 66-72.

Wigert, H., Johansson, R., & Berg, M. (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Science, 20*, 35-41.

Wijnroks, L. (1999). Maternal recollected anxiety and mother-infant interaction in preterm infants. *Infant Mental Health Journal, 20*(4), 393-409.

Wille, D. E. (1991). Relation of preterm birth with quality of mother-infant interaction at one year. *Infant Behavior and Development, 14*(227-240).

Winnicott, D. W. (1958). Primary maternal preoccupation. In *Through pediatrics to psychoanalysis* (pp. 300-305). New York: Basic Books.

Wolf, M. J., Koldewijn, K., Beelan, A., Hedlund, R., & deGroot, I. J. (2002). Neurobehavioral and developmental profile of very low birth weight preterm infants in early infancy. *Acta Paediatrica, 91*, 930-938.

Wood, B. L., Hargreaves, E., & Marks, M. N. (2004). Using the Working Model of the Child Interview to assess postnatally depressed mothers' internal representations of their infants: A brief report. *Journal of Reproductive and Infant Psychology, 22*(1), 41-44.

Wyly, M. V., Allen, J., & Wilson, J. (1995). *Premature infants and their families: developmental interventions*: Singular Publishing Group.

Yin, R. K. (1992). The case study method as a tool for doing evaluation. *Current Sociology, 40*, 121-137.

Yin, R. K. (1994). Discovering the future of the case study method in evaluation research. *Evaluation Practice, 15*, 283-290.

Yin, R. K. (1997). Case study evaluations: A decade of progress? *New Directions for Evaluation, 76*, 69-78.

Yin, R. K. (2009). Designing case studies. In *Case study research: Design and methods* (Vol. 5, pp. 25-66). Los Angeles, CA: Sage.

Yin, R. K. (2012). A brief refresher on the case study method. In *Applications of case study research* (pp. 3-20). Los Angeles, CA: Sage.

Zeanah, C., Danis, B., Hirshberg, L., Benoit, D., Miller, D. B., & Heller, S. S. (1999). Disorganized attachment associated with partner violence: A research note. *Infant Mental Health Journal, 20*, 77-86.

Zeanah, C. H., & Barton, M. (1989). Internal representations and parent-infant relationships. *Infant Mental Health Journal, 10*(3), 135-141.

Zeanah, C. H., & Benoit, D. (1995). Clinical applications of parent perception interview in infant mental health. *Child and Adolescent Psychiatric Clinics of North America, 4*(3), 539-554.

Zeanah, C. H., Benoit, D., Barton, M., & Regan, C. (1995). Representations of attachment in mothers and their one-year-old infants. *Journal of the American Academy of Child Psychiatry, 32*, 278-286.

Zeanah, C. H., Benoit, D., Hirshberg, L., Barton, M., & Regan, C. (1994). Mothers' representations of their infants are concordant with infant attachment classifications. *Developmental Issues in Psychiatry and Psychology, 1*, 1-14.

Zeanah, C. H., Mammen, O. K., & Lieberman, A. F. (1993). Disorders of attachment. In C. H. Zeanah (Ed.), *Handbook of infant mental health* (1st ed., pp. 332-349). New York: Guilford.

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